A CONTRIBUTION TO SUPPORTING AND UNDERSTANDING THE END STAGE RENAL FAILURE EXPERIENCE

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With special thanks to the men who gave up their time and shared their experiences with me by participating in this research, it was much appreciated.

DECLARATION

I declare that this thesis was supervised by Dr Adrian Neal and Dr Julie Highfield. Apart from these collaborations, this thesis is my own work and it has not been submitted for a degree at any other University. Authorship of any papers arising from this work will be shared with the above named people. A written summary of the findings from the empirical study will be sent to participants and presented to relevant staff involved in the study.

SUMMARY

There are 30,000 people in the UK who are on dialysis or that have received a transplant for chronic kidney failure (Stein & Wilde, 2006). Those with a diagnosis of End Stage Renal Failure (ESRF) face a gruelling treatment regimen with dialysis providing only 5% of the function two healthy kidneys would supply (Stein & Wilde, 2006). Patients face many changes to their lifestyle and these are often difficult to manage. The treatment necessary for such a condition is complex and includes restrictions to diet and fluid intake as well ingestion of medication and attending dialysis. Many patients struggle with adhering to this treatment and it is important to have an understanding of the psychological factors that contribute to this issue. Understanding the experience of being diagnosed and treated for ESRF for specific groups of patients is an important area of research if the best quality care is to be provided. This thesis is made up of three chapters, the first two are a literature review and an empirical paper that focus on two under-researched areas in the field of ESRF.

Those with ESRF often struggle to adhere to prescribed medical treatments with rates estimated to be between 50-80% (Christensen, 2000; Morgan, 2001). The social and psychological effects of this diagnosis on adherence have been well recognised by the research. Chapter one presents a critical review of the literature that considers psychological factors of adherence to the treatment for ESRF in its entirety (rather than dietary restrictions or medication intake alone) in the last ten years. The review reveals a number of important psychological factors related to adherence to ESRF treatment. The review finds evidence to support the argument that psychological factors associated with adherence are an important consideration for supporting this group. The review highlights many of the limitations of the current literature and identifies directions for future research.

Chapter two presents an empirical study exploring working age men's experiences of ESRF and haemodialysis. There is a lack of research into the experiences of specific groups with this diagnosis and treatment experience. This includes working age men, and there are no qualitative studies of this group. The paper focuses on the experience of diagnosis, treatment and coping using Interpretative Phenomenological Analysis. Findings revealed three superordinate themes these were: 'The many sides of the HD treatment experience', 'Coping the best way you can' and their experience of ESRF as a 'Hidden diagnosis'. Clinical implications and directions for future research are then discussed.

Chapter three is a reflective paper highlighting some of the issues that arose for the researcher during the research process. This paper considers the different roles of the researcher within and outside the research context, how they have converged and the impact they have had. They include reflections that may be beneficial to future researchers in this area.

CHAPTER 1.

THE PSYCHOLOGICAL FACTORS OF ADHERENCE TO DIALYSIS: A REVIEW OF THE LITERATURE

This paper has been prepared for submission to the following journal: *Health Psychology Review*. Further preparation is required in accordance with manuscript guidelines (Appendix A), including amendments to: style, page numbering, the text within the tables and the addition of a title page. These amendments have been delayed to enable easier reading and consistency throughout the thesis. *Word count: 5,603 (excluding footnotes, table and references).*

1.0 ABSTRACT

The treatment of End Stage Renal Failure is complex and multifaceted. The success of the treatment relies on the adherence of patients to individual medical advice. Rates of adherence to dialysis are reported as being between 50-80% (Christensen, 2000; Morgan, 2001). Research has aimed to identify factors that impact upon adherence in an attempt to address this issue. Psychological factors have been reported and reviewed in the literature but have not been considered as a separate, in-depth topic for review. This review focused on literature published since 2000 due to two previous reviews published at this time (Baines & Jidal, 2000: Morgan, 2001). The aim of this review is to address this gap by critically reviewing the literature and identifying the psychological factors relevant to adherence and their clinical application. Control, coping, relationships, beliefs about illness and mental health were identified as the most relevant factors. This paper considers the strength of these findings and the possible application to renal services.

Keywords: End Stage Renal Failure, Renal Failure, Adherence, Compliance, Concordance. Psychology, Dialysis, Haemodialysis, Peritoneal Dialysis, Renal Replacement Therapy.

1.1 INTRODUCTION

Individuals diagnosed with End Stage Renal Failure (ESRF) have kidneys that are no longer functioning well enough to support life, and so require Renal Replacement Therapies (RRT) such as dialysis. (A glossary of relevant medical terms can be found in Appendix B). Renal failure is characterised by a reduction in the effectiveness of kidney function; specifically removal of toxins, regulation of fluids in the body, regulation of blood pressure, control of red blood cell production and maintenance of bone health. The most common reasons for ESRF are diabetes and vascular disease.

Patients with renal failure in the U.K make up 0.05% of the NHS workload yet receive 1-2% of the overall budget (National Service Framework (NSF) for renal services, 2004). Factors contributing to this are the expense of long-term treatment, an increasing population and an increase in the incidence of medical conditions that may lead to renal failure. Contributing to the overall cost of renal services is the financial impact of non-adherence to treatment, leading to losses in staff time, unfilled dialysis slots and increased likelihood of emergency admissions. The literature estimates the range of non-adherence to be between 50-80% (Christensen, 2000; Morgan, 2001) although rates as low as 9% have been recorded for specific elements of the renal failure treatment regimen (e.g. medication and diet) (Lam, Twinn & Chan, 2009).

1.1.1 Defining Adherence

One of the difficulties in reviewing the adherence literature is the lack of an accepted working definition. Terms such as adherence, compliance and concordance are commonly used in literature and health policy documents. In

2003 the World Health Organisation (WHO) published a document looking at adherence in health worldwide and suggested the following definition:

> '…the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.'
> WHO, 2003

In arriving at their definition the WHO (2003) stressed that the term compliance was too closely associated with a culture of blame to be appropriate and therefore endorsed the term adherence. They argue the difference between these terms lie in the role of the patient as an active participant in adherence rather than a passive, compliant, bystander. However, the 2010 white paper 'Liberating the NHS', which focussed on the ideology first seen in learning disabilities, 'no decision about me without me', uses both the terms adherence and compliance interchangeably. This semantic flexibility highlights a primary issue with regard to terminology within the literature.

In 2009 the National Institute of Clinical Excellence (NICE) produced a document specifically addressing non-adherence in medication. NICE (2009) acknowledges that both the information given by professionals and the way in which non-adherence is dealt with is vital in addressing adherence with patients. These guidelines comprehensively explored ways of working with patients who do not adhere to treatment, stating that professionals need good interpersonal skills and sufficient time with the patient. Despite comprehensive guidelines the paper does not fully address the perspective of the patient, instead assuming that a patient finding it difficult to adhere has not been given enough information. Furthermore it

does not account for those who actively choose not to adhere, even when aware of the consequences, and the ethical and clinical dilemmas faced by staff. Interestingly the consideration of adherence is entirely absent from the National Service Framework (NSF) for renal services (DoH, 2004).

In summary the body of adherence based literature poses a challenge to any reviewer, as it is a serious and provocative subject, lacking a shared working definition across health services. For the purposes of this systematic review the author will use the term adherence, as it is the most accepted term in the literature.

1.1.2 Measuring Adherence

In addition to problems with definition, measuring patient adherence is also a challenging and complex issue, across both renal services and other specialties. For example in its strictest form adherence is the total and complete subscription to a medical regimen but, this may be an unrealistic expectation as non-adherence is not always deliberate, and complete adherence is not always necessary for a satisfactory outcome. For example hypertension studies have adopted and adherence rate of 80% to define 'good adherence' (WHO, 2003).

The lack of definition clearly presents a problem when evaluating and comparing the available research as well as specifying the level of non-adherence presenting in health settings. In ESRF there are a number of measures commonly used to assess adherence, these include:

- Biochemical Measures: Potassium (K), Creatinine, Albumin, Urea.

- Inter-dialytic Weight Gain (IDWG): The total weight gained between dialysis sessions, demonstrating the excess fluid patients have taken on, therefore, it is mainly used to indicate adherence to fluid restriction.
- Skipping or Shortening: Being absent for planned sessions of Haemodialysis (HD) or Peritoneal Dialysis (PD) and the total time on dialysis recommended by the consultant being shortened by the patient.
- Self Report/ Relative report: Patients giving details on how adherent they have been to aspects of their care, commonly used with those on home dialysis. Relatives can also report on how adherent family members have been.

1.1.3 Psychological Factors and Justification for the Current Review

Research shows that depression is common in renal failure (12-40%) and that hospitalisation for psychiatric disorders is high compared to other health conditions (9%) (Christensen & Ehlers, 2002; Kimmel, Thamer, Richard & Ray, 1998). These high rates appear to be a consequence of a long-term unremitting treatment as well as the social consequences of being a renal patient (i.e. identity, family role, lack of control) (Kimmel, 2002). In recent reviews these factors have been linked to adherence (Baines & Jindal, 2000; Morgan, 2001). Papers have reviewed individual parts of the dialysis regime (e.g. diet, medication) but few papers have considered the regimen as a whole and it is this regimen in its entirety that the patient is asked to adhere to. Although research papers and reviews have looked at the importance of psychological factors in adherence across medical settings no review paper has, to date, brought together this information to establish what psychological factors are important to renal population adherence and how this information has been used to improve outcomes for this population.

In 2000 and 2001 two literature reviews considered adherence in RRT (Baines & Jindal, 2000; Morgan, 2001). Within these two reviews some psychological factors (quality of relationships with staff and family, support, distress, anxiety, mental health concerns) were highlighted as contributing towards adherence. In spite of identifying these factors both reviews failed to address application of the psychological factors into renal services for both staff and patients: this review aims to bridge this gap in the literature.

1.2 AIM OF THE REVIEW

The overarching aim of this systematic review is to consider the literature examining psychological factors contributing to adherence to the RRT regimen (i.e. the regimen as a whole not the individual components) in adults; focused on the last ten years as past reviews have explored the preceding time frame. This paper further aims to consider how psychological factors inform practice. To achieve this, the following questions have been selected to guide the process:

1. What psychological factors are central to patient adherence on renal replacement therapy?
2. How has this information been used to inform clinical practice?

1.3 SEARCH STRATEGY

Articles between January 2000 and February 2011 were searched within: Psychinfo, Web of Knowledge, Medline and CINHAL (therefore including a general database as well as databases specialising in psychology, nursing and medical literature to comprehensively cover the area). Search terms were ‘adherence’, ‘compliance’ or ‘concordance’, ‘dialysis’, ‘renal replacement therapy’, ‘haemodialysis’, ‘peritoneal dialysis’, ‘continuous ambulatory dialysis’,

'CAPD' and 'psychology' (psycholog* to capture variation). All resulting abstracts were then considered for suitability. This resulted in 176 papers across the selected databases. Following this the articles were examined and those irrelevant to the review excluded. The exclusion criteria were: papers that were published prior to 2000, only addressed a specific element of the dialysis regimen, paediatric papers and those that made no comment on the psychological factors of adherence. Papers that commented on the entire dialysis regime were published 2000 or later, were peer reviewed and commented on the psychological factors of adherence were included for review. Following this citation searches of the remaining articles were performed. This resulted in 12 articles being selected for review. (For records of exclusions see Appendix C).

1.4 REVIEW OF THE LITERATURE

In 2000 and 2001 two literature reviews considered adherence to renal regimens. Within the body of these two reviews some psychological factors (quality of relationships with staff and family, support, distress, anxiety, mental health concerns) were reported. Despite this, both papers failed to explore the need for psychological input into renal services for staff and patients. This may overestimate the ability of staff to be psychologically minded without the presence of training or consultation. This review hopes to further the identification of psychological factors, but also to relate these factors to clinical application. Papers were reviewed by considering a number of key areas: quality of the study in terms of methodology, measurement and consideration of the psychological factors and how authors have suggested these could be important in adherence and in terms of clinical application.

1.4.1 Question 1: What psychological factors are central to patient adherence on renal replacement therapy?

Key psychological factors affecting adherence identified in the literature search were: control, coping, relationships, beliefs about health and illness, and mental health

1.4.1.1 Control

Cvengros, Alan, Christensen and Lawton (2004) explored perceived control and preference for control in adherence within 49 renal patients as measured by IDWG and by use of questionnaires. This paper used reactance theory: the theory that restricted behaviour becomes more desirable to individuals. The authors suggested that individual differences in how people react to the restrictions of renal treatment can predict non-adherent behaviour. Lower levels of personal control and an increased preference for information and involvement were found to be associated with poorer adherence. This study suggested that screening for these characteristics could help services to respond to what helps different personality types to adhere to treatment. The sample was relatively small for a quantitative study (N= 49, power analysis not reported but described as limited) and the measures of perceived control were not well validated (preference for information and preference for behavioural involvement subscales). There was also a low return rate of potential participants (47%) this may also have biased reported results. Many studies in health have used theories relating to personality type to try to predict and address non-adherence- these have been largely unsuccessful and widely criticised (e.g. Dunbar-Jacob & Schlenk, 2001: Kaplan & Simon, 1990). The use of a reactance model assumes a wilful defiance to healthcare advice, which this author feels places the patient in a negative light. This may impact on

attitudes of health care professionals' beliefs about patients being uncooperative. When evaluating adherence studies one needs to be mindful of the measures that have been selected and if they can validly support claims about patient adherence. Cvengros et al. (2004) used IDWG as measure for adherence (mainly indicative of adherence to the fluid restrictions) however, the authors make more generalised claims about adherence to the renal regimen.

McCarthy, Shaban, Boys and Winch (2010) considered the patient view of adherence and the effect this may have on adhering to treatment using a qualitative methodology (thematic analysis). The authors felt that without the patient's view adherence interventions inevitably fail, and this had been lacking in the literature. This paper acknowledged how patients often felt judged by health professionals with regards to adherence. Patients felt professionals did not appreciate the impact of adjustment to treatment and having a reduced sense of control over what they were experiencing. The importance of reaching a realistic agreement that worked with patients' lifestyle was central to the idea of promoting adherence, resulting in the idea of 'adhered to in principle… tweaked in practice' (McCarthy et al., 2010, pp 249). This paper was only based on a small sample of patients (N=5), however this is appropriate with qualitative methodology employed here. It is also only based on those on PD, who dialyse themselves at home, therefore it may be that views of self care and adherence are difference to those on hospital based programs.

1.4.1.2 Coping

Christensen (2000) explored ways of screening patients by identifying coping styles with the aim of fitting them to the most appropriate treatment. This paper

developed a model based on the existing evidence. According to the model, more active coping styles (i.e. being involved in treatment decisions) appear to result in better adherence to home dialysis, more passive coping was better suited to centre based dialysis. It concluded that adherence can become an adaptive form of control, often perceived as lacking for this group. However, the paper assumed the patient has some control over treatment choice and that this is a mutually agreed decision; in practise this may not always be the case. The author based this model on their own body of publications and a subsequent longitudinal study, also by Christensen, has added support. Therefore, it is difficult to draw strong conclusions from this paper as it is based on an exclusive selection of papers reflecting one researcher's perspective.

Using a black South African population Khechane and Mwaba (2004) investigated how patients cope with treatment related stress and if this was related to adherence. Patient coping style was assessed using the Coping Strategy Indicator (CSI), and a 'problem solving' approach was found to be correlated negatively to IDWG (indicating better adherence, r= -.428). There was no reported effect of gender, marital status or employment. However, a 'problem solving approach' was the least used strategy in this population. Further consideration of how this style may be used to help this population was not explored. If this coping style can be taught to individuals as a skill, then this may have useful clinical application. The authors do not consider whether other types of problem solving styles could be useful to different parts of the regimen, given that the use of IDWG would only support an improvement for fluid adherence. In addition, any conclusions of this paper may also only apply to this specific population.

Table1. Summary table of review articles

Authors	Year	Primary Author profession	Aim	Sample	Methodology	Strengths	Weaknesses	Summary of psychological factors	Origin
Christensen	2000	Academic psychology	To form a framework for the study of patient adherence	N/A	Conceptual Paper	Considers that the literature overlooks differences within the renal group. Acknowledges that adherence is difficult to measure	Looks at authors own work. Assumes patient is active participant in clinical decisions	Active/Passive coping style congruence with treatment choice	US
Cvengros, Christensen & Lawton	2004	Academic psychology	To investigate the role of perceived and preference for control in adherence	HD N= 49	Quantitative	Considers value of predicting adherence prior to treatment.	Small sample size needs more established measures. IWG measure of adherence, just one dimension.	Personality type, control	US
Khechane & Mwaba	2004	Academic psychology	Whether certain coping styles are associated with better adherence	HD N= 50	Quantitative	Specific population. Focus on problem solving - positive	Only uses IDWG as a measure of adherence. Black South African population, limited generalisability	Active problem solving style associated with better adherence in this population	South Africa

Kovac, Patel, Peterson & Kimmel	2002	Medical	To examine links between patients satisfaction with care/ staff and the effect on adherence	HD N= 79	Quantitative	Researcher unaware of hypothesis. Multidisciplinary.	US black population, limited generalisability. Only looked at depression scale no consideration of other psychological issues. Need to establish causality of satisfaction/staff relationship	Satisfaction with care staff, particularly Nephrologist.	US
Krespi, Bone, Ahmad, Worthington & Salmon	2004	Clinical Psychology	To qualitatively identify patients beliefs about adherence. To develop a questionnaire from this data.	Qual N= 16 Quan N= 156	Qualitative/ Questionnaire development	Focus on individual meaning and belief to increase adherence. Some unexplored issues, misperceptions about treatment is this due to lack of information or a disbelief of information	Straight from qualitative to questionnaire, does one undermine the other philosophically	External/ internal control, self blame,	UK
Kutner , Zhang, McClellan & Cole	2002	Medical	To investigate whether a number of psychosocial factors are predictive of adherence	HD N= 119 PD N= 51	Quantitative	Multi measurements of adherence inc self report. Smoking sig associated with non-adherence (more general health priority)	No acknowledgement of different treatment plans/ diagnoses. No association with staff satisfaction and adherence, no consideration of implication of reporting dissatisfaction while on treatment.	Perceived control, depression, perceived effect of RRT predicted poor adherence	US

McCarley	2009	Nursing	To propose Motivational interviewing as a useful therapeutic approached to non-adherence in ESRF	Not applicable	Conceptual Paper	Patient centred approach	No empirical evidence. No thought to ethics of the used of therapeutic techniques without consent or specialist skills/training	Hope, empowerment, relationships with staff	US
McCarthy, Shaban , Boys & Winch	2010	Nursing	To examine the patients perspective of the factors that may contribute to non-adherence	PD N= 5	Qualitative	Considers patients view of adherence	No future suggestions of how to address adherence	Control, impact on lifestyle	AU
Newmann & Litchfield	2005	Public health research	Patients views on how professionals can assists patients to complete adequate dialysis	Modality and number not specified	Qualitative	Acknowledges life before dialysis not just 'patient'	Negative use of language regarding the patient 'fail'. No integration of the psychological factors with medical factors. No methodology section.	Relationships , support, control	US
O'Connor, Jardine & Millar	2008	Psychology	To apply Leventhal's self-regulatory model to ESRF to predict self-care behaviours	N= 73	Quantitative	Used a pre-existing model to explore psychological factors	Fails to make suggestions to take data forward.	Illness belief representations and emotional illness representations predict adherence	UK

Sağduyu, Şentűrk, Sezer, Emiroğlu & Őzel.	2006	Psychiatry	To compare psychiatric morbidity and QoL evaluations in HD patients and Transplant patient	HD N= 34 Transplant N= 30	Quantitative	Used relatives and patient feedback	No objective measure of adherence. Explored HD and transplant fails to specify which results and discussion point are specific to which group	Poor mental health associated with non-adherence	Turkey
Untas et al.	2011	Medic lead but multidisciplinary	To investigate the influence of social support and other psychosocial factors on mortality, adherence.	HD N= 32352	Quantitative	Physician diagnosed depression rather than screening methods. Large scale international study (12 countries)	Psychosocial factors measured by one self-report measure.	Cultural differences between countries. Fails to consider if the social support is a consequence of HD	US (lead author)

1.4.1.3 Relationships and Social Support

Papers have highlighted the relationships between patients and professionals as an important psychological factor in adherence. One paper investigated satisfaction between staff care and caregivers' relationship to adherence (Kovac, Patel, Peterson & Kimmel, 2002). This paper used an African American population only and is therefore limited in its generalisability (N=50). Patient satisfaction with doctors and ancillary staff was positively associated with attendance for dialysis and better biochemical outcomes (urea, potassium). Satisfaction with nephrologists was associated with comparatively better attendance, time on dialysis and blood results. This was shown to be most important relationship for levels of adherence. This paper only measured depression and failed to acknowledge that other types of psychological distress may also be important (e.g. disease specific distress, anxiety). It was not speculated upon why the doctor-patient relationship is different to that of other staff and a predictor of higher levels of adherence. The study looked at those who have been on HD long enough to form relationships; the psychological state of new dialysers may be quite different. The conclusions in this study are based on correlational data, therefore the direction causality cannot be assumed and there may be latent third variables that account for this relationship. Due to this no inferences can be drawn.

McCarthy et al. (2010) focused on the importance of the patient view of adherence and the effect this may have on their adherence to treatment. This qualitative study uses case studies and thematic analysis to illustrate the social context of adherence. It looked at compliant patients to gain an understanding of adherence and asked patient views on the factors affecting their adherence. Outcomes from the case studies

included social aspects as positive influences upon adherence, including support from other renal patients, support groups and enjoyment of home and clinic visits (interaction). Identity was also considered important, specifically, not being only identified as a PD patient. This study also highlighted the importance of a joint understanding of terminology. The paper considered the methodology and approach it used appropriately, and was reported within the paper. However, it relied on the discrepancy between patient goals and behaviour and did not give consideration to patients who are fully informed and actively choose to not adhere. The authors acknowledged health professionals' role in engaging with the patients' perspective and how their routine and lifestyle may interfere with adherence. Furthermore, the study only interviewed PD patients limiting is generalisability to other groups such as those on HD.

McCarley (2009) presented evidence from the literature that patient-led decisions result in decreased mortality at four year follow-up. The paper suggested that renal staff (primarily nursing) employ motivational interviewing techniques to increase patient involvement and decision making. Although there is positive data from other health settings regarding the use of motivational interviewing the paper presents no renal based evidence for use of this technique with this population. There is no suggestion of training or supervision by a qualified professional- this needs to be addressed to ensure both quality control and safe practice in service delivery. This research was also sponsored by a biomedical company that manufactures and sells HD machines, which may have biased the findings. McCarley (2009) is however, the only paper that discussed the understanding of adherence between patient and staff as a possible barrier to research; this alone makes this a stand out conceptual paper.

Contrary to the above findings regarding staff relationships effect on adherence Kutner, Zhang, McCelland and Cole (2002) found no significant relationship between dissatisfaction with staff, perceived lack of staff encouragement and indicators of non-adherence in HD.

Untas et al. (2011) undertook a quantitative, international study (N= 32,332) that explored the relationship between social support, psychosocial factors, mortality and how they related to outcomes in ESRF; including adherence. The study, based across 12 countries, uses the KDQoL-SF (Kidney Disease Quality of Life Scale - Short Form) and multiple measurements of adherence. The study reported cultural differences between countries: in North America dissatisfaction with family time predicted the skipping of HD sessions; in Europe, Australia and New Zealand feeling like a burden on the family predicted the shortening of HD sessions; and in Japan isolation and dissatisfaction with family time and support predicted high levels of IDWG. This study illustrated that there may be important cultural factors to consider when researching adherence in ESRF. The authors however failed to comment of the cultural sensitivity and available norms for the psychosocial measure (KDQoL-SF).

Newmann and Litchfield (2005) used qualitative methods and the existing literature to report insights into the 'renal lifestyle'. The paper discussed the process of adjustment, the 'pre-dialysis life' and perceptions of health professionals. Impersonal treatment by health professionals increased the number of skipped HD treatments and was an indicator of increased risk for hospitalisation. There is no clear methodology section and the number of participants is unspecified, being described as 'nearly 50'. It is unclear if this papers aim was to be a literature review, qualitative research or a

personal account of renal treatment by the author. The paper identifies that psychological factors (adjustment, QoL) are relevant but separates these from medical outcomes with no consideration of integration. The lack of clarity about aims, it methodology and unclear authors' position significantly limits the value of this paper.

1.4.1.4 Beliefs about Illness and Health

O'Connor, Jardine and Millar (2008) used Leventhal's model of self regulatory illness (Leventhal, Benyamini & Brownlee, 1997) to investigate beliefs about ESRF and how these can predict adherence behaviour. The paper (N=73) used biochemical measures of adherence as well as psychological questionnaires (Hospital Anxiety and Depression Scale, Illness Perception Questionnaire- revised and The Brief Coping Orientation to Problems Experience). Illness representations (a specific element of the Leventhal model) were found to predict levels of self care over and beyond clinical and medical factors (e.g. modality of treatment, diagnosis). Emotional illness representations predicted non-adherence but depression was not found to predict non-adherence. The authors speculated illness-specific distress may be a predicting factor for non-adherence, and that this may need consideration and further adaptation of the model. The measures of coping were acknowledged as not specific enough to this group and therefore potentially invalid for this study. Participants completed the questionnaires three weeks before medical measures of non-adherence were carried out. The authors do not consider that this may have influenced patient behaviour in the subsequent weeks. Also there was no consideration of the specific diagnosis and its affect on illness representation (e.g. if a patient is transplantable) although this is true of all of the reviewed studies.

Krespi, Bone, Ahmad, Worthington and Salmon (2003) considered patients' views and beliefs about their ESRF by conducting qualitative interviews with 16 participants. The themes were then used to construct a renal specific questionnaire which was then trialled (N=156). The qualitative interviews, which were analysed using thematic analysis, revealed that patients had often misunderstood the medical guidelines and the role of dialysis in managing diet and fluid intake (e.g. the idea that dialysis would cleanse the body of bad foods and therefore these were allowable). These misunderstandings may be an important consideration in communication between health professionals and patients. These results suggest that the relationship between the treatment team and patient could be central to improving adherence through efficient and transparent communication. The interviews also highlighted issues of self-blame for some renal patients and perceptions of HD as dominating and controlling their lives. These psychological factors may be important in the ongoing management of those diagnosed with ESRF. The paper struggled to adequately separate and define adherence from adjustment, and there was no measure of adherence apart from self report, limiting the clinical utilisation of the findings.

1.4.1.5 Mental Health

Kutner et al. (2002) looked at patients undergoing HD (N=119) and PD (N= 51) and examined predictors of non-adherence including depression, perceived control over future health, perceived effects of treatment and if patients smoked tobacco. The study used non- health specific depression screening tools (Primary Care Evaluation of Mental Disorders, Brief Patient Health Questionnaire) and the KDQOL-SF. No age range was stated so it is unclear what population was captured. Measures of adherence included missed sessions, shortened HD sessions and phosphate levels. A third of HD

and PD patients had at least one indicator of non-adherence. Treatment modality did not predict non-adherence. Those patients who were more likely to skip dialysis sessions, were younger, more likely to be black and from a lower social economic background. Current smoking habits were significantly associated with all three adherence indicators. Shortening of treatment sessions was predicted by a lack of perceived control over future health, depression and perceived effects of ESRF on everyday life. Depression also predicted shortening of treatment sessions. However, there is no attempt to further explore the meaning of these predictors or to consider interactions between them. For example it is plausible to hypothesise that those experiencing depression may struggle to actively engage in management of their health due to the characteristic features of depression such as reduced levels of motivation, increased hopelessness, and a negative outlook about the future.

Sağduyu, Şentűrk, Sezer, Emiroğlu and Őzel (2006) compared psychiatric morbidity (as measured by Hospital Anxiety and Depression Scale (HADS)) and Quality of Life (QoL) in HD and post-transplant and its impact on adherence (N= 64 (n= 30 transplant, n= 34 HD)). Results showed that lower anxiety and depression scores were related to a better QoL and that poor mental health had a negative impact on adherence. There are limited measures of adherence in this study; no biochemical methods are used, with a reliance on patient and relative reports which lack objectivity. This paper aimed to look at both those on dialysis and those that had been transplanted however; it fails to consistently separate this data both in results and discussion, which makes it difficult to generalise conclusions relating to the HD population.

O'Connor et al. (2008) found that higher patient reported emotional illness representations and illness representations (as measured by the Illness Perception Questionnaire, IPQ) predicted non-adherence, but depression did not. The authors speculated illness-specific distress may predict adherence and that this may need further investigation. It may be that general models of mental health cannot account for the specific factors of specific chronic health conditions.

Psychological factors have clearly been identified by the existing body of literature. The review has identified a number of reoccurring themes, most relevant to this population. Having identified these factors, this leads into the next question to guide the review; considering how this information is applied to clinical practice.

1.4.2 Question 2: How has this information been used to inform clinical practice?

Of the reviewed literature, there has been some suggestion for clinical interventions that may improve adherence. However, studies that suggest psychological and psychosocial interventions often do not go as far as to acknowledge that many skills represented are specialist and may require training, ongoing support and supervision. Suggestions were made for training staff in interpersonal and communication skills (Kovac et al., 2002), and Motivational Interviewing techniques (McCarley, 2009). Newmann (2005) placed importance on the staff-patient relationship in improving adherence and outcome, however then calls for more successful behavioural modification and it is unclear how these two things would work in partnership.

Some papers consider targeted interventions to health-specific distress (O'Connor et al., 2007), issues related to treatment and QoL (Sağduyu et al., 2006), and focussed

educational intervention (Krespi et al., 2004). Kutner et al. (2002) also recommended specific interventions for patients that were smokers as this was the biggest indicator for non-adherence. Christensen (2000) suggested further research into patients coping style may lead to the development of future interventions. Untas et al. (2011) found social support was an important factor in adherence and suggested that further research into improving social support was needed. Studies may suggest psychological and psychosocial interventions, but often there is a failure to acknowledge that some skills may require training and represent specialist skills.

It is apparent that the identification of psychological factors has led to suggestions of how this information may inform practice. However, the actual clinical application has to date been limited in the published literature.

1.5 DISCUSSION

1.5.1 Summary of the Review

The aim of this review was to identify psychological factors in the research regarding adherence to the dialysis regimen in ESRF and how these have been and may be applied to clinical practice.

The importance of psychological factors upon adherence has clearly been identified by the existing body of literature. The current review has identified a number of reoccurring themes, most relevant to this population: coping style, social support and relationships, beliefs about illness and mental health. However, the issue of an accepted working or research definition of adherence is not addressed by this

literature undermining its ability to utilise the results. Having identified these findings there is also an astonishing lack of evidenced clinical application.

1.5.2 Limitations and Future Research

1.5.2.1 Defining adherence

There are difficulties with the published literature. The largest single factor being the absence of a shared understanding of the language of adherence, there is also little consideration given to how the research can address this issue. The lack of shared definition or indeed language makes meaningful comparison of studies problematic. As such a key recommendation is that the need for greater homogeneity of definitions and terminology. Another key limitation in the literature is related to the methods employed to collect data. The methods used often fail to account for whether non-adherence is wilful or accidental (e.g. hospital transport being late, family commitments). Perhaps this is also linked to the fact that this area is under researched and these patients may even represent a separate research population within HD which needs exploring further.

1.5.2.2 Measuring Adherence

Many of the studies reviewed here have also only measured one indicator of adherence, although the papers often made claims for a more generalised level of adherence within their discussions. Studies aiming to formalise the best way to measure and interpret adherence in ESRF would benefit this area of research in terms of quality and comparability.

The papers represent research across different countries and health systems, and this will affect the measurement of, and response to, non-adherence. The authors' lack of

knowledge of health provider context beyond the NHS may have limited the ability to comprehensively review the papers in context.

1.5.2.3 Adherence in context – provider and patient

Non-adherence is a politically sensitive issue in the NHS in terms of targets and wastage. The research fails to address the experience and possible consequences of being labeled non-adherent by the health care provider. This may result in research failing to appreciate the effect of external factors acting upon the patient. Research exploring the experience of being a non-adherent patient, including experiences beyond the treatment setting, would give an insight into the patient experience and may uncover any consequences this label may have on patient experience of care. Similar work into the staff perspective may also be useful in providing input into how to approach patients that are non-adherent.

It appears there has been no research into the function of non-adherent behaviours. A more in depth understanding of why patients are non-adherent may help renal services work with patients to achieve adequate levels of adherence on a case by case basis. Also there is very little consideration to the possible protective factors non-adherence may provide. Many papers speculated that non-adherence may provide patients with a level of control over their situation; it would be useful to explore this further.

When considering psychosocial factors it must be highlighted that these are culturally sensitive, expectations of family support, for example, may be vastly different in the U.K., North America and Japan. Therefore, future research may need to acquire an understanding of the cultural context of adherence to provide services that are most suited to the patient.

1.5.2.4 Psychology and Adherence

There are relatively few papers produced by psychologists, and given the identification of important psychological factors in adherence this is troubling. Policy documents have not helped to clarify psychology's role in renal services. The word 'psychology' appears 16 times in the renal NSF but there is never the specific mention of a psychologist. This leaves one wondering how the psychological skills necessary to apply this data will be or are being disseminated. The majority of papers being authored by non-psychologists may be one explanation as to the lack of expansion in the psychological data. It may be that the required knowledge base and skills are outside the authors' realm of expertise. A more multi-disciplinary approach to research may help facilitate a more holistic and comprehensive picture of this area. Patients do not exist in a compartmentalised health context where their psychological wellbeing and medical needs exist separately. Therefore, services approach to meet patient needs must aim to reflect this.

1.5.4 Conclusion

ESRF patients face strict demands as part of their treatment these include: fluid intake, dietary restrictions, medication regimens and adherence to the dialysis process itself; both reviews of the literature and individual studies have acknowledged this challenge. Many studies of adherence to the renal regimen acknowledge the importance of psychological factors. However, these factors have often not been considered in conjunction with medical intervention but in isolation of them. Services need to aim to be multidisciplinary and provide a service to both the patients' medical and psychological needs. This should be a core aim of providing an efficient comprehensive, modern service.

This is a clinical area where there appears to be a conflict between the creation of a naturalistic or statistical definition of adherence. Nephrology is guided by the interpretation of many biochemical measures. However, people exist in a social context beyond biochemical parameters. This is where psychology can make a meaningful difference to bridging the gap between the biochemical measures and the experience of being an individual with ESRF. This could allow the definition of adherence to be understood in a meaningful way for both patient and practitioner.

In conclusion the literature agrees that psychological factors have an impact on adherence and that working with these factors may improve adherence however, little has been done to implement psychological interventions. The specific role of psychologists within this field has also been largely absent; the need to be psychologically aware is recognised but with little consideration as to how this may be implemented and by whom.

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CHAPTER 2.

WORKING AGE MEN'S EXPERIENCES OF DIAGNOSIS AND TREATMENT OF END STAGE RENAL FAILURE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

This paper has been prepared for submission to the following journal: Qualitative *Health Research*. Further preparation is required in accordance with manuscript guidelines (Appendix A), including amendments to: formatting, the numbering of sections, the font size of the main text and figure and the figure will be appended as a separate document. These amendments have been delayed to enable easier reading and consistency throughout the thesis. *Word Count 7, 520 (excluding tables, quotes and references).*

2.0 ABSTRACT

Patients with End Stage Renal Failure require life sustaining treatment by dialysis or transplant. Haemodialysis, one method of dialysis, is an invasive treatment procedure where by the blood is removed from the body and cleansed via the dialysis machine. Qualitative research has revealed that dialysis patients report coping, control, adjustment and lifestyle restrictions as being challenging. However, the research to date has not focused on specific groups within this population; this study's aim was to explore the experience of working age men on hospital based haemodialysis. Six men of working age were interviewed and the transcripts analysed using Interpretative Phenomological Analysis. Three superordinate themes were identified: 'The many sides of the HD treatment experience', 'Coping the best way you can' and 'Hidden illness'. Clinical implications and further directions for research are highlighted.

Keywords: End Stage Renal Failure, Men, Haemodialysis, Qualitative, Interpretative Phenomenological Analysis, Chronic Illness.

2.1 INTRODUCTION

2.1.1 Introduction to renal failure

Patients with renal (kidney) failure in the U.K make up 0.05% of the NHS's workload, yet these services receive 1-2% of the overall budget (National Service Framework for renal services (NSF), 2004). Individuals with End Stage Renal Failure (ESRF) will need treatment for the rest of their lives and each year 5,000 new cases are diagnosed in the U.K. (Stein & Wild, 2006). The most common reasons for ESRF are diabetes and vascular disease. ERSF is characterised by a reduction in the effectiveness of kidney function; specifically the removal of toxins from the body, regulation of fluids in the body, regulation of blood pressure, control of red blood cell production and maintenance of bone health. This reduction in function has far reaching consequences for the individual, and treatment is essential (Stein & Wild, 2006). Treatment options for renal replacement therapy (RRT) include dialysis, of which there are three types: Haemodialysis (HD), Continuous Ambulatory Peritoneal Dialysis (CAPD/PD), Automated Peritoneal Dialysis (APD); or renal transplant (live or cadaveric) (See Appendix B for a glossary adapted from the NSF for renal services (Department of Health (DoH), 2004).

2.1.2 Psychological Effects of Diagnosis and Treatment for Kidney Failure

The NSF for renal services, which addresses renal service provision, identified psychological factors as being an important consideration for this group (DoH, 2004, 2007). However, the emphasis is on psychological preparation for treatment rather than ongoing support. On becoming a renal patient, individuals are faced with the need to adjust to loss of body function, strict treatment regimens and

lifestyle restrictions required to maintain life. An individual's survival often depends on strict diet and fluid restrictions, medication regimens and regular RRT. The process of adjustment often involves the need to integrate changes into the individual's self-concept, and thus may shape a new identity (Petrie, 1997). Given these factors it is unsurprising that many individuals experience psychological difficulties while adjusting. As such, it is important to provide a high quality, holistic service to renal patients which would include psychological support throughout the course of the condition.

Evidence indicates that 20-30% of the ESRF population suffer from depression, but that this is often undiagnosed or under-recognised (Chilcot, Wellstead, Da Silva-Gane & Farrington, 2008). However, there is little research investigating depression in pre-dialysis patients to provide meaningful comparisons (Kimmel, 2002). Research also shows that hospitalisation for psychiatric disorders are high compared to other health conditions (Christensen & Ehlers, 2002; Kimmel, 2002). These high rates appear to be connected to the long-term unrelenting treatment approach as well as the social consequences of being a renal patient (i.e. identity, family role, lack of control) (Kimmel, 2002). Results of a small quantitative study of 15 male renal patients comparing centre HD, home HD and PD dialysis modalities indicated that those on centre HD regimes experienced more dialysis stressors and experienced a lower level of psychosocial adjustment (Courts & Boyette, 1998). Depression, anxiety and despondence can have far reaching consequences for engagement with services, especially adherence to treatment (Christensen & Elhers, 2002).

2.1.3 Haemodialysis

HD is the focus of the current research and the most common type of treatment in the UK (65% HD: 35% PD/CAPD, Stein & Wild, 2006). The process of HD is time consuming, with a mechanical system taking over from the kidneys, and it usually takes place in a hospital setting. It is common for people to dialyse up to four times a week with these sessions lasting three to five hours (Stein & Wild, 2006). In addition to attending for dialysis those with ESRF, as previously stated, often need to adhere to strict dietary and fluid restriction, medication regimens and cope with the associated side effects (Faber, de Castell & Bryson, 2003). Although treatment is life-sustaining, this dependency on a time-consuming treatment often results in individuals feeling they have little space for living a 'normal' life (Hagren, Pettersen, Severinsson, Lutzen & Clyne, 2005). Nagle (1998) found HD patients report a sense of 'abiding' with technology, as well as dealing with the losses it represents, and named this a 'reluctant partnering'.

2.1.4 Psychological Effects of Haemodialysis

Challenges to self and identity, in the chronically ill, and its consequences has been cited in health publications, including renal failure research (Charmaz, 1983; Gregory, Way, Hutchinson, Barrett & Palfrey, 1998). Research shows that the feelings of restriction and a lack of control are a common experience of HD patients (King, Carroll, Newton & Dornan, 2002; Al-Arabi, 2006; Smith, 1996) and that perceived control over health care has an impact on psychological adjustment to diagnosis. Gaining a sense of control, however, appeared to result in a balance between positive and negative affect (Bremer, Haffly, Foxx & Weaver,

2009). One study into the experiences of diabetic renal disease patients found that stoicism was a factor in coping, although it was also evident that individuals struggled to maintain presentations of themselves as resilient; revealing feelings of desperation and victim representations (King et al., 2002). Courts and Boyette (1998) identified that renal patients often appear physically well and report that others lack understanding of the challenges they face during their treatment regimens.

2.2.5 Qualitative Research Exploring Individual's Experience of Kidney Disease

Qualitative methodology allows researchers to move away from the medical model of symptoms and treatment and to look at the broader consequences for the individual of diagnosis and treatment of chronic health conditions. From this research recurrent themes have emerged regarding the patients experience of ESRF, what individual patients view as the difficulties, restrictions, and the consequences and their emotional response to these.

Qualitative research has explored the experience of patients undergoing dialysis. Of these papers, in the last ten years, five studies have explored the experience of individuals undergoing more than one modality of dialysis, and five studies have looked specifically at HD. None have been restricted by age or gender. A common theme in the qualitative literature is patients describing a loss of identity as a result of diagnosis (King et al., 2002; Tong et al., 2009). Restriction and control was also found to be a source of frustration for this group and a sense of increased control found to be positive for patients who frequently felt their life was out of their

control (Molzahn, Bruce & Sheilds, 2008; Tong et al., 2009). (See Appendix D for a summary table of past qualitative research themes).

A review of the key qualitative research available in 2003 suggested furthering this research by exploring the "distinctive aspects of the experience of specific groups [*in order to*] creatively reconsider issues such as difference between various groups living on dialysis" (Polaschek, 2003, p. 308). The paper highlights the importance of qualitatively gathered findings to services in tackling issues such as non-adherence to therapeutic prescriptions. Providing sensitive and patient centred services must include an understanding of patients' experience of their diagnosis, treatment and the health system itself. Qualitative research has the ability to collect experiential based data that can achieve this.

2.1.6 Present Study

Existing research suggests that further research should look at specific groups, both in terms of dialysis modality and gender/age/pathology within ESRF (e.g. Molzahn et al., 2008; Polaschek, 2003). Although there is a body of research on ESRF much of this research has been quantitative, rather than focusing on the lived experience of individuals, and the available papers have not focused in on specific groups within the renal population. It has not received the attention and focus that other health concerns have, e.g. cancer [despite evidence that Quality of Life (QoL) is similar for ESRF patients and patients with terminal malignancy (Saini, Murtagh, Dupont, McKinnon, Hatfield & Saunders, 2006)].

University Hospital is a general hospital located in Coventry. The main renal unit on this site and its satellite units across the region serve patients from the Coventry and Warwickshire area, providing a service for approximately 388 HD patients per year.

The staff team have identified working age men with ESRF as having a unique and distinct psychological reaction to the diagnosis and HD treatment experience. They were identified as being difficult to engage and seem to warrant more referrals to the psychologist attached to the renal service. The aim of this study is to use explore the lived experience of this clinically identified group; guided by the themes identified in previous qualitative research.

Previous research has looked at the general group of 'renal patients', whereas working age men, have only been considered in two papers, both quantitative (Courts & Boyette, 1998; Sayag, Kaplan, Shapira, Kahan & Boner, 1990). Courts and Boyette (1998) found that men on hospital based dialysis treatment were significantly more likely to experience a greater number illness stressors and have poorer adjustment than those on home based treatment. They also hypothesised about the aspects that may be unique to this population, such as challenges to employment and loss of traditional male role. Sayag, Kaplan, Shapira, Kahan and Boner (1990) compared men on HD and post renal transplant in terms of adjustment and found a similar level of adjustment between these two groups; although transplanted patients had better sexual function and more positive opinions of medical staff. There has been no research specifically on the qualitative experience of being a man with ESRF.

2.1.7 Aims

The aim of this study is to explore working age men's experiences of ESRF specifically those treated with hospital based HD using an Interpretative Phenomenological Analysis (IPA) methodology, using a semi structured interview (Appendix E). These questions were used as a guide to facilitate participants sharing of their experience.

2.2 METHODOLOGY

2.2.1 Design

Interpretative Phenomenological Analysis (IPA) was chosen as a methodology. IPA was selected because of its distinctive approach, focusing on participants' personal accounts in detail, attempting to understanding the uniqueness of their experiences as well as shared processes (Smith, Flowers & Larkin, 2009). IPA has a phenomenological focus, exploring an individual's personal perception of events, experiences and the meaning these hold (Smith, Flowers & Larkin, 2009). Other methodologies do not offer this individual insight. This was thought particularly relevant given the study's focus on the lived experience of this group, a concept which is conceptual and personal in nature.

2.2.2 Participants

The sample consisted of six men with ESRF (average age= 43.5 years, average number of months on HD= 65). All men were recruited from the University Hospital HD unit (demographic details summarised in Table 2). Men were excluded if they were over 65 years of age, had been on dialysis less that 6

months, had received a transplant in the last 5 years, had a diagnosis of diabetes, did not use English as their primary language or were unable to understanding the requirements of participating in the study.

Table 2: Demographic Summary table

Participant Pseudonym	**Age**	**Duration on HD**	**Employment status**
John	41	7 years	Not working
Tom	47	12 years	Not working
Mark	49	1 year	Not working
Sandeep	46	6 years	Self-employed
Peter	30	8 months	Not working
Niraj	48	7 years	Part time work

2.2.3 Semi-structured Interview

The semi-structured interview was adapted from an existing IPA interview that covered the areas cited in the research aims and questions (Smith and Osborn, 2008; Appendix E). This interview had already been used with renal patients (substantiated with the first author). The interviews encouraged participants to tell their story rather than be strictly led by the interview schedule to gain the personal experience of each participant.

2.2.4 Procedure

2.2.4.1 Recruitment

A flow chart outlining the procedure for recruitment and data collection can be found in Appendix F. Potential participants were identified and contacted through Clinical Nurse Specialists (CNS) or a Consultant Nephrologist at the University Hospital site. Only men dialysing on the main hospital site were approached. A participant information sheet (Appendix G) was posted to men meeting the

inclusion criteria. This outlined why they had been contacted and what would be involved in participating in the study. The sheet also stated that participation was voluntary and would not affect their clinical care in any way. If participants agreed to take part they were briefed on their right to confidentiality and any possible exceptions to this, the consent process and given an opportunity to ask any further questions. Once the briefing was completed participants were given a consent form to complete providing they wanted to continue (Appendix G).

Eleven men, at University Hospital, met the inclusion and exclusion criteria for the research and were approached for involvement in the study, six were interviewed. Three declined to be involved, one was transplanted before a meeting could be arranged and one was transferred to a satellite unit before he could be contacted. Therefore, the six men are a highly representational sample of the research site.

The semi-structured interviews were conducted in a private room at University Hospital renal service; these lasted between 40-70 minutes. The researcher then verbally debriefed the participant and provided contact details and guidance regarding how to proceed if they become distressed by any part of the interview procedure.

2.2.4.2 Ethical Approval

Ethical approval for the study was granted by Coventry University Ethics committee, Birmingham, East, North and Solihull Research Ethics Committee on behalf of the NHS National Research Ethic Committee and from the University

Hospital Coventry and Warwickshire NHS Trust Research and Development Department. (Appendix H)

2.3 DATA ANAYLSIS

2.3.1 The process of IPA

The interviews were the transcribed verbatim and identifying information removed.

The data was analysed using IPA as detailed by Smith and Osborn (2008): see Appendix I for a description of these stages of analysis, a section of coded transcript (stages 1-2), and a sample of pages from the master list of super/subordinate themes with evidencing transcript quotes.

2.3.2 Researcher's Position

During data collection the principal researcher was a female Trainee Clinical Psychologist on placement at the University Hospital Renal Service. This study focuses on men, and the researcher's gender may have had an effect on her position to the sample; this was reflected upon prior to commencing the interviews. As a clinician, the researcher has a preference for working from an integrative perspective with a focus on narrative therapy. As a result the researcher may have been unknowingly influenced by clinical work she was carrying out in parallel. Examination of the transcripts and coding was carried out throughout the analysis process by a researcher familiar with the project and a neutral researcher. This checking of the analysis by other professionals should have minimised any bias or overly personal perspective.

2.3.3 Validity and Credibility

Yardley's methods of maintaining validity and credibility were employed to ensure the analysis obtained depth, breadth and sensitivity (Yardley, 2008). The analysis kept closely to the original transcripts, this was constantly checked throughout coding. At the preliminary stages of analysis a section of transcription was given to a researcher who is uninvolved with the research and to the clinical supervisor to compare coding. This ensured that themes produced from analysis were not confined to the viewpoint of the primary researcher (Smith & Osborn, 2008). Sections of transcripts were also checked at later stages of analysis. Emerging codes were then discussed with the research team who have access to the original transcripts. These discussions allowed opportunities for previously overlooked themes to be captured. Transcripts and research notes were kept at every stage of analysis establishing a 'paper trail' from transcription to presentation of the superordinate themes.

2.4 FINDINGS

2.4.1 Superordinate themes

Three superordinate themes developed from the data analysis that were common to all participants and highlighted both their similarities and differences: "Experience of Haemodialysis", "Coping" and "Hidden diagnosis". The themes along with their subordinate themes are shown in Table 3. (This table along with evidencing quotes can be found in Appendix I). The interviewers' quotes have only been included where needed to set the context of the participants' reply.

Table 3: Table of superordinate and subordinate themes across all participants

T1: The many sides of the HD treatment experience	T1a: The burden of HD
	T1b: Emotional Impact: 'That's very difficult'
	T1c: Support within the renal community
T2: Coping the best way you can	T2a: Finding a way through it
	T2b: How did I get here?
T3: Hidden Diagnosis	T3a: Public profile of ESRF
	T3b: Tangible illness

2.4.2 Theme 1: The many sides of the HD treatment experience

T1: Subordinate theme a: The burden of HD

Participants described the challenges of HD as a treatment; treatment was often described as leading to just as many difficulties as the disease itself. All of the participants described the treatment as a challenge in some way; this included the treatment as being painful, inconvenient and relentless. John describes the physical effects of being on the dialysis machine:

> John: Yeah, physically, you just feel horrible your heads a little bit fuzzy and you just don't feel right and then when you do actually go low *[have low blood pressure*] it just like one of these things where you just go low and you get sick and things like that which you

> don't want to do and erm [sighs]…so you kind of worry about that thing going on. (Pg.3, 72- 76)

Peter highlights that one of the challenges is that the treatment can be painful and invasive.

> Peter: then they stick two giant needles in your arm [Laughter] which are quite painful… er… then after they've stuck the two of them in, they basically hook you up to the machine… (Pg.1, 15- 17)

One participant saw a challenge to treatment as being other patients' negative attitudes to being there and how these challenge his efforts to view treatment positively.

> John: Cos you may have known renal patients, you may have spoke to some and they can moan…and they're quite good at it as so you don't want to hear them all the time you want to hear the good, so you have a chat with the girls *[nurses*], you don't want to be listening to moaning all the time. (Pg.16, 398- 402)

Treatment was seen as having changed over time and improvements in modern treatments were acknowledged although most felt it did not give a quality of life and this was seen as a challenge to treatment; that it was not a good treatment but a good enough treatment. Sandeep shows below as well as demonstrating his difficulty with the treatment regimen.

> Sandeep: You just...it does keep you alive...er...that's it basically I…I don't think it a quality…you're not getting a quality still...there's no quality there...you're going on alive breathing but you can't enjoy your food, can't eat what you want to eat…you can't drink certain things...or a bit too much to drink one day cos you don't pass er…you're not passing any urine like

> so you know it's...yeah, its a struggle basically, it's a struggle. (Pg.9, 211- 217)

Participants who had been diagnosed for a number of years also spoke about the long term effects of the treatment and getting older on dialysis. Some felt they had not received adequate information about how long term HD would affect them and others feared further decline.

> Niraj: …since I've been on haemodialysis, since I've not been able to function and work as, as, as much as I used to that has slowed and I hate that that's the most frustrating aspect… I worry it'll continue… I don't want to be a doddering old git. (Pg.14, 341- 344)

T1: Subordinate theme b: Emotional Impact: 'It's very difficult'

The emotional impact of treatment was also described by all participants. Many of the participants talked about fluctuating emotions depending on how HD was affecting them at a given time. Some reported that treatment had reduced their ability to tolerate emotional situations. Participants described feeling resentful, helpless, vulnerable, angry and depressed; especially early on in the treatment experience. Some of the men could not vocalise the overwhelming nature of the emotions they were dealing with; but could explain how they felt about the dialysis machine. Below Mark shows his mix of positive and negative feelings towards treatment; highlighting his appreciation for treatment and his anger at it:

> Interviewer: So if I had asked you to describe you relationship with the dialysis machine what would you say?
>
> Mark: [Laughter] I'd love to put my fist through it [Laughter]…no… no, the things keeping me alive…er and to understand what it does and how it works and how to set it up … I think it's a bit of a miracle really that thing... to be honest.. to be serious

> it is a bit of a miracle that machine so… so… it's the only thing that's keeping me alive so I've got to treat it with a bit of respect… does that make senses [Laughter]. (Pg.9, 219- 227)

One participant said he did not believe there was an emotional aspect of coping with HD this represents divergence in the samples views on the emotional impact of HD

> John: [Laughter] I don't think there is one, personally I don't think there is...erm...the funny thing is, I'm not really fussed about, I know this sounds really stupid, I don't know if this sounds really stupid but I'm not really fussed about me. (Pg.15, 371- 374)

For most of the participants' emotions were seen as difficult to deal with and constantly shifting depending on their health. Here Tom struggles to find the words to relate his emotions about treatment:

> Interviewer: Some of those are quite practical things, how about on an emotional level?
>
> Tom: That is very difficult. Extremely difficult… (Pg.11, 263- 266)

T1: Subordinate theme c: Support within the renal community

The social aspects (social support, losing other patients) of HD were also an important sub-ordinate theme within the treatment experience. These experiences were mainly positive interactions with staff and other renal patients. The meaning of these experiences varied, although a common theme was making the social

experience a positive way of passing the time on treatment. Mark's quote shows the positive nature and value gained from social aspects of HD.

> Mark: That support is very important to me. Because even though I've got to meet a lot of people here and even though I've moved from one ward to another ward I've still been put on a ward where I know a couple of people and we're still in the same frame of mind… so I'm still alright that's why I'm still on a high… because I've still got people around me where I enjoy their company… so to speak… and they don't pull you down… and they don't moan [Laughter]. (Pg.15, 381- 386)

Tom's shows the difficult side of social interaction and getting close to people on the unit.

> Tom: I've know I think it's about 6 people who I've been close to who we've lost over the past couple of years and that is it's scary but it either hardens you or make you think…yeah…I find that very unsettling in that sense.(Pg.18, 443- 446)

In summary, this theme exhibited the many challenges of HD, the men spoke of getting through the treatment in terms of feeling physically unwell, pain and the invasive nature of the treatment. The emotional impact was also a recurrent theme, some of the men felt dealing with depression and an overwhelming amount of emotion was part of the treatment experience. Social elements of treatment were largely positive with patients gaining a lot from each other's company whilst dialysing.

2.4.3 Theme 2: Coping the best way you can

T2: Subordinate theme a: Finding a way through it

Finding an approach to coping seemed important to the participants, how adaptive this was varied between participants. Some participants talked about how a positive attitude helped in coping with treatment and ESRF. This positive approach was often cited as being a forced choice; participants felt that if negativity replaced this positive attitude they would be unable to cope.

Often participants' coping approach was multifaceted, for example staying positive and carrying on for the sake of others (especially for their children); below Sandeep illustrates how his family provides his motivation to keep going and his *"get on with it"* way of coping:

> Sandeep: Well I've got no choice really, I've got kids so… its… so… err… you know can't just sit in bed, like you know I don't feel like getting up but I get myself up and I get on with it…you know. (Pg.9, 222- 224)

Niraj describes what he thinks is necessary to cope with the condition and treatment. He emphasises that maintaining a life beyond dialysis should be the purpose of treatment.

> Niraj: Firstly… you've got to stay positive, you've got to have a positive mental attitude it's, it's, it's… don't live to dialyse, dialyse to live… (Pg.16, 222- 394)

Day to day coping was also described; both in terms of limiting disappointment when plans have to be changed, because of their health. Tom highlights this,

describing living day to day and making the best of what you can do when you feel able:

> Tom: Take each day as it comes. If you feel ok do what you can do, whether it's shopping visiting friends, tidying your house, internet, going out meeting friends or whatever and the opposite is if you don't do well, you don't do anything you go to bed… (Pg.10, 258- 261)

Some expressed how viewing HD as a job they had to do was a useful way of coping with the demands of HD. It appeared this helped participants deal with the change to a reduced or non-working status; below mark explains HD as work:

> Mark: I had more energy and it's all to do with… organisation… you've got to organise yourself. Dialysis treatment's like going to work… that's how I get my head around it. I make myself a packed lunch I make myself a flask and I'm going to work for 6 hours that's how I get my head around it... if some things got to be done do it, get on with it. (Pg.8, 198- 203)

Humour was often described as being part of the coping process; this was represented in the interviews both by what participants said and the presence of humour within the interview itself. Laughing at themselves or at their situation; this humour was often light, but at times could also be dark. John described how he laughs at the issues for men on dialysis:

> John: I've got to be honest I poke fun about being a man on dialysis because of things [suggestive face] don't work and err… I just poke fun at all that whole business cos… I don't take it seriously, I mean as I said I don't pass fluid I don't do anything whatsoever and it's just hilarious when you hear people having to go to the loo and you think ha I don't do that… (Pg.22, 556- 561)

In Niraj's account he jokes with the interviewer that his life could be short and therefore the future was not a major concern to him.

> Interviewer: And do you think about the future much
>
> Niraj: … how long are we talking [Laughter]
>
> Interviewer: that might be part of the answer
>
> Niraj: Er…no… I look at short term futures in terms of what I want to achieve in 12 months or whatever… (Pg.14, 353- 362)

T2: Subordinate theme b: How did I get here?

Another area of coping uncovered by the analysis was individuals search for how they had arrived at the situation they found themselves in. This mainly presented in the transcripts in two forms, why this had happened and having a story to tell. Participants' thoughts on the reason they had ESRF varied from being punished and not knowing why, to seeing diagnosis as a reason for negative events or just accepting it as an act of random chance. Some of the participants still seemed to be searching for their answers why others seemed to have an accepted way of thinking about this. As part of making meaning some of the participants questioned their situation as can be seem in Mark's quote below:

> Mark: Because I felt like why me… why should I be here I'm only 50… why should I be here? Why me? Er… taken out of the system the way I have been… cos I've always worked and I love my job...er…and I resented the disease. (Pg.6, 144- 146)

Peter felt the meaning of his illness was that he was being punished although he did not feel he had done anything to be punished for.

> Peter: …yeah…yeah I mean I would say that I see myself as someone who is being punished… for… how I am erm… I've not brought this on myself or anything like that and then I'm being punished… (Pg.8, 200- 202)

Tom felt that ESRF was responsible for negative events in his life and how his live had been since diagnosis:

> Tom: …I lost my marriage and everything because of it. (Pg.5, 128- 129)

Another way of making meaning of their situations was having a story. This seemed to be an important part of making meaning of the diagnosis and treatment process. Some stories illustrated current challenges to the patients, some their journey to diagnosis and some their story from diagnosis to present day. Sandeep describes his story of his pre-dialysis life to diagnosis, illustrating how little time he has to comprehend what was happening to him.

> Sandeep: Yeah I was very outgoing, very tough, I used to train a lot… you know, kept my body in good shape…very, very fit…I did martial arts, did boxing, did weight training…didn't smoke, didn't drink, had a good diet and everything so it was a big shock that you know one day I had a bit of a temperature and er within 2 days I was in hospital and that was the end of that… (Pg.4, 95- 100)

Being able to give an account seemed to give a sense meaning to the men. In the following quote Mark comments on many patients having a story to tell:

> Mark: And it's…er…it's er… different for everybody cos I've talked to other patients and they've all got their own little story to tell… (Pg.3, 65- 66)

In summary the participants employed many personal coping styles. Having a sense of meaning of the illness or a story of their illness were themes across cases. In the interviews some had a blameless approach to meaning '*just one of those things'* and seemed to demonstrate more acceptance for their situation, while those who felt punished or wronged seemed to struggle. Many approaches to coping were described and staying positive, having some control and humour all featured prominently.

2.4.4 Theme 3: Hidden Diagnosis

T3 Subordinate theme a: Public profile of ESRF

The public profile of ESRF was an issue for participants. There were frustrations about having a chronic illness that very few people had heard of or had any knowledge. John illustrates this and his frustration at the situation below:

> John: The whole kidney thing it's just so small no one knows anything about it. I think that's where it's wrong I think...it...needs to be brought out a little bit more...because as the... you folks say there's more and more people coming onto it but they've no idea.
> (Pg.19, 485- 488)

Participants described having to educate friends and family about their illness and cope with people minimising their condition, both due to its low profile and the lack of obvious outward symptoms. Some participants compared it to other conditions as a way of establishing how other conditions had gained a certain status. Cancer was the most frequently cited but one participant also gave the FAST campaign for stroke awareness as an example of how the profile could be raised:

> John: I do think , er…as I said earlier on I think the main problem is, is that there's not anything out there... you know...you hear about you know I mean obviously they're all horrible ..obviously you've got your cancers, strokes heart attacks, diabetes and things like that [sighs] and you just… you don't know anything there's nothing out there in the world that's telling you to get this checked like that advert for a stroke...the FAST is it? (Pg.18, 462- 468)

Peter felt the lack of understanding of ESRF had had a serious affect on his ability to access the benefit system as is illustrated in this account:

> Peter: So that's why I've gone back to college to retrain er… because I don't feel that I'm getting the support from the correct people that don't understand, that don't know where to put you within the benefit system… cos obviously some people are working, some are not, some are well, some are not so… so there's no… you're not… oh he's got kidney failure we'll give him these benefits, here what he'll have… it's oh how well are you? What can you do? What can't you do? (Pg.17, 418- 425)

However, some participants reported shying away from sharing their diagnosis with others unless absolutely necessary. There was a conflict between others not understanding and the frustration of this and wanting to remain private or not marking themselves out as different to others. This is illustrated by Sandeep's experience of sharing his condition with others in his community:

> Sandeep: …and if you tell someone, you know, I'm not allowed this food they don't understand, well Asian people don't understand any way, they totally don't understand. It's er…really frustrating... I get the feeling Asian people don't want to know if you're ill. (Pg.7, 158- 162)

Recognition of the lack of knowledge and understanding beyond the immediate renal community was echoed throughout the cases. In these accounts the men describe the lack of available information, here Peter describes the little information people might know and relates it to people's failure to recognise the impact on his life:

> Peter: it just seems to be… like if you went and spoke to Joe Blogs off the street and said if I gave you renal failure what's the first 3 things that come into your head and a lot of them would probably say it was an old person illness a lot would say, when your transplant due [Laughter] er… and then they'd probably know dialysis but they wouldn't know anything else. What impact it makes on your life…erm… I mean it's very, very hard … so the level of understanding people have is non-existent, there isn't any. (Pg.18, 454- 463)

T3: Subordinate theme b: Tangible illness

'Hidden Diagnosis' is further elucidated by the second subordinate theme, tangible illness. Participants often commented on the invisibility of their illness as a drawback, although the men appeared to appreciate being able to choose who they shared this with. Looking well or not being able to show someone their illness was described in terms of having to prove their illness to others. This frustration with lack of visibility was mixed with a personal resistance to define ESRF as an illness, with most preferring the term condition, those who did see it as an illness however, would not use this label to others also preferring the term condition. John describes his view of diagnosis and those with ESRF appearing well:

> John: I don't rate it as an illness you know there are illnesses you know out there but if you look out there [points toward unit] some of them look quite alright you wouldn't think there was anything wrong to look at them that there's anything wrong with us so you

> know if you look at cancer patients they...look like there ill whereas I don't think none of us do half the time depending on the day of course but I don't think it's an illness I just think we...it's a condition we have. (Pg.8, 194- 201)

Peter also highlights appearing well and the lack of tangible illness for ESRF but he goes on to further make this point with examples of visible impairments

> Peter: Cos on the outside I don't look any different from a normal person it's not like I've got a limb missing or something, you take a leg of or an arm off or if I lost an eye… looking at me there's no difference, they only difference is my arm where the needles go. (Pg.13, 309- 312)

In summary, there was a conflict between the negative and positive aspects of ERSF being a hidden diagnosis. Overall the frustration at the diagnosis having a low public profile seemed to outweigh having the choice to share the information.

2.5 DISCUSSION

2.5.1 Summary of findings

Analysis of the six interviews revealed three superordinate themes that were common across all participants: 'The many sides of the HD treatment experience', 'Coping the best way you can' and ESRF as a 'Hidden diagnosis'. Within the first theme the participants described the challenging nature of treatment, that it could be painful, inconvenient and did not provide a good quality of life. The emotional impact was also a feature of the participants' feedback, often this was difficult for the participants to put into words, although their accounts indicated the seriousness of this impact and their struggle to articulate it further highlighted this. Depression, feeling vulnerable, anger and helplessness were some of the emotions described as

well as fluctuations in their emotions. Social interaction was a more positive part of the HD experience, with all participants commenting on the importance of peers, who could relate to their experience as well as losing peers to the disease.

'Coping the best way you can', the second superordinate theme, came from many accounts of how the participants approached dealing with their life as a renal patient; staying positive, having a reason to carry on and using humour showed the variety of approaches. Finding meaning was often connected to coping, the most frequent explanation offered by participants was a random act of chance and. Others described their situation as unfair, as if they were being punished, this appeared to reflect where the individual was in their journey to accepting and coping with their diagnosis.

ESRF was often described as being hidden to some extent. Either by the individual themselves; not wanting to share their diagnosis, or the low awareness of those outside the renal setting and also a lack of obvious physical symptoms. There were conflicting accounts, both within and across cases, of the benefits of having the choice to share this information and the frustration at not being able to demonstrate the seriousness of the condition.

2.5.2 Discussion of the findings in relation to the current literature

Below the findings of this study are considered in the context of the current literature. Similarities and differences between the findings are explored.

2.5.2.1 'The many sides of the HD treatment experience' and the current literature

Treatment being invasive and difficulty adjusting to the treatment regimen have previously been reported in this area (Al-Arabi, 2006; Faber et al., 2003). The focus of this study was on men on HD therefore the experiences described were specific to this modality. These were incorporated into the theme of 'Experience of treatment' and further represented by the subordinate theme 'Challenges of HD'. This could indicate that there are different challenges to different parts of the treatment regimen or treatment modality (HP, PD and CAPD). The painful, invasive nature of the treatment was one of the challenges that the men described and reported struggling to accept. The social aspects of the hospital based HD appeared to be a mediating factor in tolerating this for these individuals.

Patients' level of support has been examined in the literature (Christensen & Ehlers, 2002; Tong et al., 2009), although the extent of the value of peer relationships and support has not been highlighted. These relationships appeared not to only offer practical support, but being in the company of those perceived to have a shared understanding, especially where groups were of a similar age, seemed especially important. Participants viewed this group as understanding their particular issues with HD, such as impact of family life and employment. Considering this in conjunction with the superordinate theme 'Hidden illness', it is apparent that experiencing this level of understanding was highly valued to assist the individual in managing treatment and overall coping. The prior research has identified this group as having a wish for normality (Lindquist, Carlsson & Sjöden, 2000). Being surrounded by a support network where HD is normalised may create

this for these individuals. This may be especially important for working men where social expectations of them being stoic or able to carry on may create added pressure to minimise their illness.

The emotional impact of treatment was also a common theme in this study and the literature, both qualitative and quantitative, has reported high levels of depression in individuals with ESRF. The word depression was used by half the sample to describe their emotional state at some point since diagnosis. Being vulnerable was also described as being an uncomfortable position for some of the men, this too is supported in previous research (Tong et al., 2009). It may be that feeling vulnerable and helpless is a particular problem for men as these are at odds with more stereotyped masculine traits.

2.5.2.1 'Coping the best way you can' and the current literature

In this sample the participants' time since commencing dialysis did not seem to reflect how well they appeared to be coping but instead the meaning of the diagnosis appeared to be more related to this. For example, Tom who blamed the diagnosis for the loss of his marriage was still finding his way to live with ESRF after 12 years, whereas John who saw the diagnosis as a 'blessing' and the end of his suffering when he received treatment described having always coped throughout his seven years on HD. This supports existing literature, which has shown those who have more negative perceptions of their diagnosis and treatment also report the have a poorer QoL, this has also been linked to individual's ability to cope (Fowler & Baas, 2006). It is clear from the data that as well as struggling to cope with some parts of their experience the men felt a pressure to cope. This

has rarely been mentioned in the literature and may be specific to this population; many (five of the six participants) of the men had families they felt a pressure to be seen to be coping for others well-being as well as for themselves.

2.5.2.3 'Hidden Diagnosis' and the current literature

The final superordinate theme, 'Hidden illness' has rarely been seen in the literature although being perceived as well and expected to live a normal live has been identified (Courts & Boyette, 1998). The topic of the public profile of ESRF and the tangibility of it as an illness has, to the author's best knowledge, not been reported. Therefore, this may represent a different level of this previous theme, individuals have reported their own understanding of the diagnosis, the impact and understanding of on their support network, perhaps public awareness is the another piece of this issue. It may be that issue is particularly relevant to a working age male population where they may struggle with accepting the ill role and with defending it. Traditional male traits and stereotypes may be more at odds with this scenario that for female or elderly sufferers. The men appeared to feel a pressure to be able to prove their illness as the extent of its effect was often hidden. However, they also described having the choice as whether to share their diagnosis as an advantage.

2.5.2.4 Men on HD

This study aimed to look at men's experiences of HD as a homogeneous group. From the discussion of the themes that revealed themselves in the data, it seems that there are some distinct areas that may be relevant to men on HD more than other patients with ESRF. Feeling vulnerable and helpless were reported emotions

in this study. These may be at odds with traditional male traits and expectations, therefore, may be a particular problem. The men appeared to feel unable to prove their illness and the extent of its effect. This may be more of a challenge to men than women who are perceived and more likely to access health services and therefore perhaps find more acceptance (both self and by society) as being seen as unwell. This group, working age men, may feel the need to defend their reduced capacity or inability to work and fulfil their role as bread winner for their family. This supports Courts and Boyette's (1998) hypothesis of increased illness stressors and poorer adjustment (in men on hospital based dialysis) being partly due to aspects unique to this population; such as challenges to employment and loss of traditional male role. This seemed especially difficult in the context of looking well and struggling to explain their circumstances to others. However, they also described having the choice as whether to share their diagnosis as a benefit; it could be argued this was a strategy to maintain a more acceptable self, both to others and themselves.

2.5.3 Limitations and Directions for Future Research

The findings of the current study are supported by the existing research, and have also provided new insights into this specific population's experience of renal failure. The study's findings must however be considered in the light of its methodological limitations.

The primary researcher was female working with a male sample group. It is possible that this factor influenced the participants (in that issues specific to being a man on dialysis may have been more difficult to discuss with a female relatively

unknown to the men) and in turn the content of the interviews. Furthermore the study represents the view of six men that are varied in age, educational and cultural background. Future research should include further specific groups to increase the depth of the information gathered.

In addition the study did not consider whether the participants had other health conditions (apart from diabetes) which may have impacted on how individuals perceive and cope with their diagnosis. This study was only able to interview those whose primary language was English; future research may think about addressing this to further develop our understanding of the different views and service needs of this diverse client group.

IPA demands that the researcher is aware of their own views and impact on the research process. IPA is a subjective methodology and represents the combination of individuals trying to make sense of their experience and the researcher similarly trying to make meaning of this. Therefore, the themes that have emerged from the research result from the content of the interviews and the researcher's understanding and interpretation of the participants' experiences. The researcher kept a reflective journal to encourage and enhance awareness of her impact on the research process (see chapter 3).

The renal unit participants were recruited from a service selected group described as "difficult to engage", therefore the researcher was exposed to a preconceived assumptions and bias toward this group. However, it is recognised that this group

agreed to take part in the research process and therefore may represent a more engaged, open group.

The theme of 'Hidden illness' has not previously been identified in the research. This theme may indicate that working age men find the lack of public knowledge about renal problem more frustrating than other groups of renal patients. Future research might aim to explore why this is. As previously stated it is possible that this group were particularly sensitive to being mistakenly seen as healthy and able to work by others despite being unemployed or only able to work minimal hours. Social expectations for the sample group are, one could argue, entirely different to an elderly sample or even a working age female sample, where not working may not be considered as unusual. Further research on the complexities of social and employment related expectations of this group, and the impact these may have on managing chronic illness, is clearly needed.

One participant identified that there may be specific cultural challenges in his attempt to be understood and heard. He believed his family to be resistant to hearing he was ill and believed this to be a cultural trait. This may suggest that there may be different challenges for individuals from different cultural backgrounds. In this case the resistance to a special diet was mentioned given that his cultural celebrations often revolved around food. It would be of interest to investigate this further.

The conflict within the participants to the lack of awareness of others of the condition and the ability to keep it hidden may be a useful consideration in the

research on forming a new identity in chronic illness. The ability to hide the illness may suggest a wish to preserve the identity of a 'well self' in the eyes of others. It would be useful to compare this to literature in other chronic health conditions with a higher profile and see if these groups feel better understood and whether that improves their experience of their illness. Future research in this area may elucidate the impact of this both in this area and in the context of the broader chronic illness literature.

Further research on working age men as a group in relation to ESRF threatening their masculinity and their male societal role would also be useful to further help understand the challenges for this group. This research may also be useful in other forms of chronic illness where ability to work is affected or illness is similarly hidden.

2.5.4 Clinical Implications

2.5.4.1 The many sides of the HD treatment experience

The burden of HD are individual and varied and supporting patients through this process is complex especially as there are certain factors services cannot adjust (e.g. time, pain, medication and dietary requirements). These challenges seem to be helped by the positive social aspects of HD. Participants felt being with a group similar in age was particularly useful. This is may be something services could offer and arrange as a useful way of providing a supportive treatment environment that does not require specialist knowledge skills or funding.

The emotional impact was described as being a difficult aspect of ESRF and some of the participants referred to having seen a clinical psychologist through the renal service and the use of a specialist service to support them. The DoH cancer reform strategy (DoH, 2007) specifies that specialist psychological support should be available for cancer sufferers and an integral part of care, it may be that this needs to be reviewed within the renal services NSF.

2.5.4.2 Coping the best way you can

Participants' consideration of a long term future on dialysis may imply that change and coping within this group is dynamic and complex. There may be many levels of gaining understanding and reappraising their situation over time. This may help our understanding of the coping patterns of this group; that a number of stages or cycles of processing may be necessary for some individuals to cope. This may help services plan how they support individuals, often there is a lot of information and support upon diagnosis, and this may need to be maintained throughout the duration of care.

2.5.4.3 Hidden Illness

The communication by participants of their frustration at the low public profile of ESRF is an interesting quandary. The usual purpose of health promotion is to raise awareness for early diagnosis and cure. However, this does not apply to ESRF as easily as other areas. Early awareness of the problem may provide an increased period of time to adjust while 'well'. However, this does not prevent the eventual failure of the kidneys. This issue may be addressed by providing good quality, easy to understand, information at service level that people may feel comfortable

to share with their social support network. Health Professionals may need to remain mindful that although it is often our responsibility to explain and give information directly to our patients, they will be repeating this process, as an information giver, in their social network.

This group, working age men, may feel the need to defend their inability or reduced capacity to work and fulfil their roles (often) as bread winner for the family. This seemed especially difficult in the context of looking physically well and struggling to explain their circumstances to others. Group support may be a useful way of these individuals exploring and processing their frustration in this area. This would follow on from the value already placed on peer support and understanding.

From this research it would appear working age men may benefit from recognition of the challenges of their diagnosis, not only within the treatment environment but in the broader social context. Services being aware, and recognising, possible frustrations about being unable to work and feeling their illness is unacknowledged may help this group feel understood. Hopefully the acknowledging, understanding and valuing of these issues would facilitate engagement. Therefore, being aware of the specific needs of working age men may help increase their engagement with renal services.

2.5.5 Summary and Conclusions

Despite an increase in ESRF and the risk factors for diagnosis this area is under-researched with respect to specific groups within this population. This paper

contributes to addressing this by reporting on the lived experience of working age men with ESRF- a previously overlooked group in terms of qualitative and quantitative research. For this group the experience of having ERSF encompasses the 'The many sides of the HD treatment experience', 'Coping the best way you can' and ESRF as a 'Hidden illness'. Having social support that was in a similar position in terms of age and expectation seemed especially relevant to this group. This may link to the frustrations of ESRF being a 'Hidden illness' and feeling others were questioning the severity of their health condition and their ability to live a 'normal' life; both socially and professionally. The combination of frustration at the lack of recognition of the seriousness of ESRF and the relief that people could not identify them as renal patients demonstrates the complex impact of this diagnosis on this group. Further research is required to build on the understanding of the experience of this group to allow renal services to provide an effective and efficient service to patients.

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CHAPTER 3.

WHEN RESEARCH MEETS REAL LIFE:

REFLECTIONS ON THE MULTIPLE ROLES

IN MY RENAL RESEARCH EXPERIENCE.

This paper is not intended for publication

Word count: 2,791

3.0 INTRODUCTION

Whilst writing the final parts of this thesis I have reflected on my time at my research site, a renal dialysis unit in Coventry. I also elected to complete a specialist placement there. This allowed me flexible access to my sample as well as daily contact with the professionals I relied on to assist with my recruitment. However, I have found myself reflecting upon the consequences of this decision; the effects being in this environment has had on me and my research and, indeed, the roles I had within it.

Balancing my clinical psychologist role with that of being a researcher within the same workspace had both its positive and its negative aspects. During this dual experience of renal services I was also the relative of an individual in renal failure and jointly attended my relative's outpatient appointments with them. I have also found myself becoming deeply aware of these two amazing organs called kidneys, having never really given them a second thought; suddenly they became rather prominent in my everyday life.

Renal failure is a relatively rare disease, however, but when working in a health speciality where everybody has a particular diagnosis it can become easy to start to believe that it is relatively common. This is not the first time I have encountered this; having worked in a children's hospital as an assistant psychologist it became more and more amazing to me that anybody gave birth to a well child. Experiencing the renal unit was to like being let into what is, in some ways, a hidden world.

3.1 REFLECTIONS ON MY ROLES IN THE RESEARCH PROCESS

3.1.1 Carrying out research on placement: keeping in the right role at the right time

When one goes to see a one man show, the performer will take on a number of roles, each one being integral to holding the whole event together. This is how I felt balancing my multiple roles of researcher, psychologist, and relative of a renal patient. I chose to be on a specialist placement at the site of my research. This decision was mainly motivated by my own convenience and prior to being on placement I did not give a great deal of thought to the meeting of these two distinctive professional roles.

One of the focuses of clinical training is to gain skills in psychological therapy. Although research makes up a significant proportion of the blood, sweat and tears offered up over the three years, for me the therapy role is the main part of the job. As a researcher, I found myself in a room with someone experiencing, through a chronic health condition, both the emotional challenges and the distress of this situation, yet it was not my role to offer any help. At times I found unsettling. Perhaps if I had decided to use questionnaires or ask for written feedback I would not have experienced this, and that would have had its advantages. However, I had previously spent two years in research using quantitative methods and this seemed like an exciting opportunity to experience something different through the research process.

During the research process I experienced feelings of impotence and of not quite knowing how to place myself in the conversation. This perhaps reflected my own fear of not being able to exist within the more familiar role of 'therapist'. Maslow once said 'if all you have is a hammer every problem starts to look like a nail', (Maslow, 1966, pp.15). This felt especially true when I found myself outside my comfort zone in the research interviews. In my reflections on this experience I have considered that as a psychologist I have a broad and varied toolbox; not just a hammer. Even in the context of providing therapy we work from a number of perspectives with a number of tools, we provide complex interventions as well as facilitating a client towards having insight into themselves and their problems. Our basic assessment, counselling skills and reflection are certainly highly relevant to qualitative methodology.

The participants in my research did not place this expectation on me so it was quite a surprise how much I continued in this role to place it on myself. Even after working in psychology for almost eight years I still struggle to accept I cannot help everyone (even, apparently, when I'm not suppose to be). I feel there is a balance to establish; I feel quite strongly that I want to go into every situation with a client with the hope that I can help. However, I acknowledge that I struggle when a positive outcome starts to look unlikely, for whatever reason. Therefore, having to hold off, to not intercede, was in itself a useful and challenging experience; becoming aware of, but not giving in to, my urge to rescue. I do not know if telling their story or the content of the interviews challenged or helped my participants, I hope so, but it

certainly helped me. I believe that the research experience, and especially balancing this with my clinical work, has brought me closer to a balance.

On conclusion of my placement, and specifically during the analysis of my interviews I found myself considering how my clinical experiences of placement may have affected my research experience and its process. There were the practical aspects: knowing the medical jargon, the Consultants' names and the set up of the unit. With regards to understanding the emotional challenged encountered, I have concluded that the individuals I worked with clinically gave me further insight into my research. The experiences described by my participants were illuminated rather than clouded by my individual work. The knowledge I gained in my renal psychologist role allowed me to be a better researcher, to be more sensitive to the experiences being described to me by my participants. It gave me the knowledge and insight to develop the questions included in my interview schedule in keeping with the Interpretative Phenomenological Analysis ethos.

In summary I do not regret my decision to choose a placement that overlapped with my research. Perhaps, retrospectively, I wish I had given it more care and consideration prior to carrying out my research. Having said that, it allowed me to get the work done efficiently but it also allowed me to complete it in a more sensitive and reflexive way.

3.1.2 Personal Experience of Renal Services

During my research I found myself in an uncomfortable and strange position on the other side of the fence, accompanying a relative to their renal appointments. It is rare to attend a medical appointment with any prior specialist knowledge, and I found it to be as equally as daunting as having none at all. My family member regarded me as being a knowledgeable advocate; which I experienced as more stressful than relying on an actual medical expert in blissful ignorance. The information provided before the appointment to aid our decision making as a family was a booklet paraphrasing a book I had read for my research, written by a Consultant who works in the renal team with which I was conducting my research. This added to my sense of it all suddenly being rather close to home in every sense. Months of reading the renal literature, clarifying medical terms with the Consultants suddenly leapt off the page and into my life.

It was not just the perceptions of my family that altered the approach to these appointments. The moment the nurse or consultant knew I had some knowledge about renal issues changed the entire tone of the appointment. We were spoken to in a respectful transparent way and choices were offered rather than directions given. This was particularly relevant to my research literature review about adherence. Much of the literature specifies that a joint decision is crucial to patients, both increase adherence to medical advice and to feel in control. My experience on this was to feel relieved we as a family had been given the choice of how to approach treatment. However, I also felt empathy and frustration for patients who were not

credited with having enough knowledge to make these decisions for themselves. The information we were provided with was accurate and detailed but sadly inaccessible to my relatives, as it was still relatively complex. Clearly my knowledge was enormously helpful to us as a family, but what about everybody else?

In psychology we often tell our clients they are the experts on themselves, they have the depth and we have the breadth of knowledge; should this be any different in health care? As a National Health Service (NHS) employee it is hard to answer this question as I approach all my own interactions with NHS services expecting a sense of equality between me and Health Care Professionals. This was perhaps the first time I truly considered that this clearly this is not the same for everybody and may make a difference to the service you receive.

As a family we decided on conservative treatment for their renal failure. I now recognise that I defended myself against the emotional impact this; being in a room discussing what were effectively end of life treatment decisions by sidestepping into my professional role. By doing this I could step out of my relative role and be practical and ask important questions. I have since worried if these decisions, that I have been instrumental helping to agree on, are the correct ones. Being a researcher is to be neutral and not to influence the information you are given or to be able to acknowledge what biases you may bring. This experience was about crossing these lines, having an opinion, making a difference. This experience made my research participants come to life, exist outside the interviews and the space I saw them in.

Although they were working age and my relative was elderly, they may all face decisions regarding conservative care one day. This is a sobering thought.

When relatives are elderly, the infirmities of age (memory, deafness and many other co-morbidities) may mean that relatives often find themselves becoming advocates to help with decisions about healthcare. I found that my knowledge through my research was a great help, but was also a great pressure. The stakes of these decisions were high and the consequences of them potentially distressing. I am glad I was able to assist in these decisions, but the task was immense and a poignant reminder of the expectations and dilemmas faced by those I had interviewed.

3.1.3 Having a common denominator (or we all have kidneys!)

I could not have predicted how aware I would become of those two organs sitting inside me during this research. A common theme of the participants making meaning of their diagnosis to cope with what had happened to then was 'why me, I didn't do anything'. This left me thinking - could I be next?

In my role as a researcher and as a psychologists in general I have often considered the psychological disorders I have come across, especially the more serious ones, and find myself thinking 'I'm probably never going to be diagnosed with this'. However, the same is not true in health work, it could be me, and I could be next. As one of the consultants I met told me on my first week, '…people are relatively well

with renal failure, right down to 30% functioning, you could be there [at 30%] right now, you could go into renal failure and be on dialysis tomorrow'.

The kidney is a unique organ in a way if you ask people to draw a kidney the shape displayed is likely to be a good approximation. However, most people could not describe to you what the kidneys function is. This is based on me having explained the basic functions of the kidney many times since undertaking this research.

Kidney disease has a very low profile, and my participants found this particularly frustrating. The level of understanding of their situation had led them to choose to not share their diagnosis, or to feel they have to prove their ill health in some way. Being on the renal unit, its atmosphere and mood, was a shock. I had a lot of experience of working on children's wards; these are usually noisy, brightly decorated places. In contrast the renal unit, in my mind, often appears to have an air of gloom about it, rows of individuals linked up to their machines a three time a week, a reminder of their dependence on this piece of technology. To me dialysis appears to make you a prisoner with a long list of rules: do not eat that, do not drink this, be here when you are told and take this pill. I imagine I would make a terrible renal patient, the type there are professionals meetings about. My own fear of being so totally reliant on something and not having my freedom makes dialysis abhorrent to me. I have tried to consider how I view dialysis after my research experience and the best I can do is to quote someone else 'Dying is easy, it's living that's hard' (Babbitt, 1975) this may be true of life but to it certainly seems true of dialysis.

Therefore, I have a great respect for anyone who is managing to get through this treatment, whether they are getting through it sticking to the medical advice rigidly, or just about managing to get by.

Researching individuals with chronic ill health draws to your awareness that neither you nor anyone else can make the problem go away. In my clinical work I could help clients' manage their distress, tolerate their treatment and deal with the range of emotional difficulties they experience, but nothing can be done to make their kidneys work. I will not pretend I was at ease with this during my research. Perhaps no one should ever be totally at ease with a life long chronic illness, perhaps this is a 'comfortable discomfort'. One papers apt title, which has come to my mind during the many phases of my research, is 'You can't cure it so you have to endure it' (King, Carroll, Newton & Dorman, 2002). For me this is the perfect summing up of renal failure and was echoed by many of the participants of my research. Treatment was valued in terms of life but often seen as much as a problem as the diagnosis itself. This research has made me appreciate my good health, and how fragile this may be. None of the men in my research had done anything to cause their renal failure, some were born with the problem that had led to kidney failure and others had been told it was just bad luck. There are many things we can do to improve our likelihood of continued good health. The idea that there are health problems we can do little to avoid or control is a frightening thought. So here, to conclude this section, is a message for my own kidneys: I know I do not look after you as well as I should but please, please, do not fail me.

3.2 CONCLUSION

Whilst wearing my research hat, therapeutic hat, and 'caring relative' hat so closely together, has left me with much to consider. This essay also mirrors my broader experience of training has been all about a balance of roles from the beginning. Therefore, it feels strangely appropriate that one of my last written pieces should be all about my many roles as I approach the end of training.

There has also something about accessing a NHS service relevant to my research that has reminded me about what people experience coming to a service. I have really valued this experience; being in a waiting room rather than collecting someone from it and being given advice rather than providing it. That is one thing I value about working for the NHS: I work for a company that I myself and my family access and rely on. This gives a sense of real belonging to my workplace and I have always had a sense of pride at being an NHS employee. Having said that, sometimes during the research experience I have felt precariously perched on the fence between the personal and the professional and perhaps that a place I would rather not inhabit too often.

One other lasting impact of my journey into the world of renal disease is I will never be able to eat a banana ever again without thinking about how it is a forbidden food to many renal patients and how full of potassium it is. It will certainly make me appreciate my freedom and good health more on a daily basis.

3.3 REFERENCES

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Appendix A:
Journal Submission Guidelines

Health Psychology Review

Instructions for Authors

SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Introduction

Submission of a paper to ***Health Psychology Review*** will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of the editor and publisher.

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Submission process

Manuscripts must be submitted by one of the authors of the manuscript. The submitting author is responsible for the article during the submission and peer review process.

To facilitate the review process ***Health Psychology Review*** accepts only online submissions. All submissions should be made online at ***Health Psychology Review***'s ScholarOne Manuscripts site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Preparation of manuscripts

Currently, ***Health Psychology Review*** can only accept manuscripts written in English. Manuscripts should be double-spaced and should be prepared in accordance with the format and style specified in the Publication Manual of the American Psychological Association (APA), Sixth Edition. Pages should be numbered consecutively and organized as follows:

The Title Page (p. 1) should contain the article title, authors' names and affiliations. It should also include an author note with authors' full affiliations and the address for manuscript correspondence (including e-mail, address and telephone and fax numbers).

In accordance with the APA Publication Manual (6th Ed.). No information that would indicate authors' identity or affiliation should be contained in the manuscript itself, all such information should be included on the title page only.
The Abstract (p. 2) must be a single paragraph that summarizes the main findings of the paper in fewer than 200 words. After the abstract a list of up to six keywords that will be useful for indexing or searching should be included.

Manuscript length
There is no formal word limit for manuscripts. Submissions should, however, be as long as necessary and authors of submissions of excessive length which do not covey ideas and points succinctly and concisely will be asked to truncate their manuscript. We also draw authors' attention to the Health Psychology Review online repository of supplemental materials that provides a permanently accessible resource of materials that are too long for the print version of the journal (e.g., oversized tables, intervention protocols, questionnaires etc.) but to which authors of articles appearing in Health Psychology Review wish readers to have access.

Style guidelines
The manuscript should follow the guidelines of the APA Publication Manual, Sixth Edition.
If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Figures should be in a finished form suitable for publication and should be numbered consecutively with Arabic numbers in order of appearance in the text.

Tables should be numbered consecutively with Arabic numbers in order of appearance in the text. Type each table double-spaced on a separate page, with a short descriptive title typed directly above and with essential footnotes below.

Competing interests
A competing interest exists when your interpretation or presentation of information may be influenced by your personal or financial relationship with other people or organizations. Authors should disclose all financial and non-financial competing interests.

Authors are required to complete a declaration of competing interests and submit it together with the manuscript. All competing interests that are declared will be listed at the end of published articles. Where an author gives no competing interests, the listing will read 'The author(s) declare that they have no competing interests'. Please consider the following questions:

Financial competing interests

- In the past five years have you received reimbursements, fees, funding, or salary from an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? Is such an organization financing this manuscript? If so, please specify.
- Do you hold any stocks or shares in an organization that may in any way gain or lose financially from the publication of this manuscript, either now or in the future? If so, please specify.
- Do you hold or are you currently applying for any patents relating to the content of the manuscript? Have you received reimbursements, fees, funding, or salary from an organization that holds or has applied for patents relating to the content of the manuscript? If so, please specify.
- Do you have any other financial competing interests? If so, please specify.

If you are unsure as to whether you, or one of your co-authors, has a competing interest please discuss it with the editorial office.

Authors' contributions
All authors are expected to have made substantive intellectual contributions to, and to have been involved in drafting or revising the manuscript. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. Acquisition of funding, collection of data, or general supervision of the research group, alone, does not justify authorship. With the submission of a manuscript, it is assumed that all authors have read and approved the final manuscript.

Acknowledgements
All contributors who do not meet the above criteria for authorship, should be listed in an acknowledgements section in accordance with the APA guidelines. The acknowledgements should be contained on the title page of the manuscript as making acknowledgements available to reviewers will compromise the masked peer-review process. Examples of those who might be acknowledged include those who provided general, technical, or writing assistance. Acknowledgement of funding/grants are also included in this section.

Proofs
The manuscript will be edited according to the style of the journal, and PDF proofs will be e-mailed to the corresponding author for final review. To avoid delay in publication, only necessary changes should be made, and corrections should be returned promptly.

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Qualitative Health Research

An International, Interdisciplinary Journal

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Editor: **JANICE M. MORSE, RN, PHD (ANTHRO), PHD (NURS), FAAN**
University of Utah College of Nursing, Salt Lake City, Utah, USA

QUALITATIVE HEALTH RESEARCH, widely referred to as ***QHR,*** is an international, interdisciplinary, refereed journal for the enhancement of health care. Published monthly, it is designed to further the development and understanding of qualitative research methods in health care settings. The journal is an invaluable resource for researchers, practitioners, academics, administrators, and others in the health and social service professions, and graduate students who seek examples of qualitative methods.

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Articles in *QHR* examine an array of timely topics such as chronic illness; risky behaviors; patient–health professional interactions; pregnancy and parenting; substance abuse; food, feeding, and nutrition; living with disabilities; milestones and maturation; monitoring health; children ‘s perspectives on health and illness, and much more. In addition, the journal addresses a variety of perspectives, including cross-cultural health, family medicine, health psychology, health social work, medical anthropology, sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

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This section of the Guidelines covers matters of *QHR* journal style, which are not subject to author preference; adherence is required.

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IMPORTANT CONSIDERATIONS

- *Qualitative Health Research* is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.
- We do not publish stand-alone abstracts, *quantitative* studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles *must be pertinent to health.*
- Write both the abstract and the text of your manuscript in *first-person, active voice.*

- For best results, review this entire document prior to preparing and submitting your manuscript.
- Proper manuscript preparation will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication.
- Improper manuscript preparation could result in burdensome revisions, lengthy delays in the review and production processes, and the possible rejection of your manuscript.

GENERAL STYLE

Authors considering submission to *QHR* should first be familiar with the journal, the types of articles we publish, and our readership. Read several recent articles published in the journal prior to submitting your work, and consider whether your manuscript is a good —fit□for the journal.

In general, *QHR* adheres to the requirements of Sage Publications, Inc., and the guidelines contained in the ***Publication Manual of the American Psychological Association*** [—*APA*□], **6th edition** (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the *APA Publication Manual,* or just *APA.* Additional help may be found online at http://www.apa.org/, or search the Internet for —*APA* format.□

Many universities and private organizations have Web sites devoted to *APA* style. However, when guidelines found on those sites, or in the *APA Publication Manual,* conflict with *QHR* Guidelines, *you must follow the* QHR *Guidelines.*

JOURNAL STYLE

GENERAL INFORMATION

This section of the Guidelines covers matters of *QHR* journal style, which are not subject to author preference; adherence is required. ***Note:*** If you still have questions after carefully reading these instructions, please refer to the sample manuscripts beginning on page 31 before contacting the QHR office.

IMPORTANT CONSIDERATIONS

Qualitative Health Research is a peer-reviewed journal. Only complete, finished manuscripts should be submitted for consideration.

We do not publish stand-alone abstracts, *quantitative* studies, manuscript outlines, pilot studies, manuscripts-in-progress, letters of inquiry, or literature reviews. Research articles *must be pertinent to health.*

Write both the abstract and the text of your manuscript in *first-person, active voice.*

For best results, review this entire document prior to preparing and submitting your manuscript.

Proper manuscript preparation will speed the peer-review process for your manuscript, and will facilitate a smoother production process if it should be selected for publication.

Improper manuscript preparation could result in burdensome revisions, lengthy delays in the review and production processes, and the possible rejection of your manuscript.

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Authors considering submission to *QHR* should first be familiar with the journal, the types of articles we publish, and our readership. Consider whether your manuscript is a good —fit□for the journal.

In general, *QHR* adheres to the requirements of Sage Publications, Inc.,

and the guidelines contained in the ***Publication Manual of the American Psychological Association*** [—*APA*□], **6th edition** with regard to manuscript preparation and formatting. Elsewhere in these Guidelines this book is referred to as the *APA Publication Manual,* or just *APA.*
Many universities and private organizations have Web sites devoted to *APA* style. However, when guidelines found on those sites, or in the *APA Publication Manual,* conflict with *QHR* Guidelines, *you must follow the* QHR *Guidelines.*

BASIC DOCUMENT PREPARATION

See also a variety of sample manuscripts beginning on p. 31.
Note: Do not use any coding or formatting that is not described within these Guidelines!

DOCUMENT SETUP AND FORMATTING

Paper size Letter, 8.5□x 11 inches, with portrait orientation. Margins 1 inch (1□) on all sides. Line numbers: None. **Line spacing exactly "double,"** with 0□before and 0□after.

ORDER OF MANUSCRIPT ELEMENTS

Compile the elements of your manuscript in the following order:
Document 1: Title page (required)
Document 2: Abstract and keywords (required). Main manuscript text (required). Notes (if any). References (required). Appendices (if any). Tables (if any)
Document 3: Figure 1 (if any)
Document 4: Figure 2 (if any)
(And so forth, with each subsequent figure in a separate document)

FORMATTING OF MANUSCRIPT ELEMENTS

Note: For ease in locating needed information, the various elements are listed below in alphabetical order, and not in the order of anticipated use.
Ellipses / ellipsis points. The proper way to create ellipsis points is as follows: Three (3) dots, preceded, divided, and followed by spaces (i.e., space dot space dot space dot space), like . . . this. If it is necessary to indicate missing words between sentences (instead of in midsentence): Place a period (full stop) at the end of the first sentence, then format the ellipsis points as noted, and begin the next sentence (with a capital letter) immediately after the last space (i.e., period space dot space dot space dot space). . . . Like this.
Font size: ***Text*** Use 10-point font for *everything* except text in tables, figures, and (if applicable). ***Tables and figures*** Use only 8- or 9-point font in tables and figures−nothing smaller and nothing larger.
Font style: ***Headings, title page, tables and figures*** use Gill Sans font style for all of these. This includes figure/table numbers, titles, text within the figures/tables, and citations or explanatory notes below the figures/ tables (if any). *Note:* If you do not have Gill Sans font on your computer, please use Arial instead. ***Main manuscript.*** Use Times New Roman font for the main body text. Also, use Times New Roman font for the *text* (not

the headings) of author ‘s notes, acknowledgments, declarations of conflicting interests, funding statements, and bios.
Italics should be used only
as appropriate in the reference list (see *APA);*
as appropriate in level-2, -3, and -4 headings; and
to introduce non-English words, or *unusual* new concepts (2 to 3 words), and then only when the new word or concept is first introduced in the manuscript; subsequent use of the same word(s) should be in regular Roman font.
Headings All headings, without exception, are to be set in Gill Sans, 10-point font. (Use Arial if you do not have Gill Sans on your computer.)
QHR uses 4 distinct levels of headings (H = Heading), including:
H Level Formatting (all headings should be double-spaced, just like the regular text)
H1 **Flush Left, Bold Text, in Title Case**
H2 *Flush Left, Italicized Text, in Title Case*
H3 *Flush left, italicized text, in sentence case, ending with a period.* At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph. Use this heading only if you have a total of four (4) heading levels.
H4 *Indented (.5”), italicized text, in sentence case, and ending with a period.* At this level, the paragraph text begins immediately after the heading, instead of on the next line. The heading is part of the paragraph.
Use *at least two* heading levels:
For manuscripts with 2 heading levels, use H1 and H2
For manuscripts with 3 heading levels, use H1, H2, and ***H4*** [***not*** H3]
For manuscripts with 4 heading levels, use H1, H2, H3, and H4
Justification of margins
All text should be *left justified.*
Length of manuscript *There is no predetermined word or page limit.* Provided they are —tight and concise, *without unnecessary repetition* and/or irrelevant data, manuscripts should be as long as they need to be. The editor might require a reduction in length if the manuscript contains material that does not add anything useful to the topic being discussed. Limits might be imposed on the number/size/length of tables, figures, reference lists, and appendices.
Line spacing *Everything, in all elements of the manuscript,* from the title page through the references and tables (if any), must be exactly double spaced. Exception: Text within a figure should be single spaced. Paragraphs are to flow, one after the other, without additional line breaks (with few exceptions; see below), and with no extra space between paragraphs.
Leave a blank (double-spaced) line between the abstract and the keywords. Leave a blank line *after* (not before) each block quote/excerpt, numbered list, or bulleted list. Use Word ‘s Format > Paragraph function to set block quote/excerpt and bulleted/numbered list indentations; note that

block quotes/excerpts and lists are to be *completely* indented (not just the first line) by .5 inches from the left margin only; *do not indent the right side.*

Quotation marks In general, use double quotation marks (e.g., —Xxxx.□) to set off quotations appearing within regular paragraphs, and to set off words being used with —special□meaning (or unusual spelling to convey special meanings within the text; e.g., —busy-ness□).In regular paragraphs, use single quotation marks to set off a quote within a quote (e.g., —Xxx, ‗Yyy, ‘xxxx.□). Note that when *closing* quotation marks coincide with a comma or period (full stop), the quotation marks go outside (after) the comma or period: —Quotation. . .last word.□

Quotations of less than 40 words should be surrounded by double quotation marks (—) and included with the regular sentences of a paragraph. Internal quotations within quotations of less than 40 words should be set apart with single quotation marks (‗). **Quotations of 40 or more words should be set as separate paragraphs,** with the entire quotation **indented .5 inches** from the left margin (this is also referred to as a —block quote□or —excerpt□). **Do not use quotation marks** for block quotes unless there is a separate, internal quotation within the larger quotation; in that case, use double quotation marks (—) for the internal quotation only.

See the special section, below, for instructions on formatting *conversation analysis.*

Keywords should follow on the same page as the abstract. Leave a blank, double-spaced line between the abstract and the keywords (see the sample manuscripts). Include keywords *selected only from the QHR Keyword List,* below. List them exactly as they are shown in the keyword list, in lowercase letters (except for proper names), horizontally across the page, in the order in which they appear on the keyword list. Try to select at least five keywords. Use the most specific keywords possible from the list provided. Individual keywords should be separated by semicolons; note that some keywords are actually two or more words, and might include commas. Do not capitalize the first keyword, and do not add a period (full stop) at the end of the keywords. You may request that new keywords be added to the list, but the words should be *general* in nature, and not specific to a narrow topic. New keywords will be added at the editor ‘s discretion.

Appendix B:
Renal Terms Glossary

Adapted from: The National Service Framework for Renal Services: Glossary of terms

- Acute renal failure (ARF): Rapid deterioration of kidney function caused by injury or illness; often reversible.
- Automated peritoneal dialysis: A form of peritoneal dialysis in which a machine is used to carry out multiple fluid exchanges, usually overnight.
- Chronic kidney disease (CKD): Abnormality of the structure or the function of both kidneys, lasting more than three months; often progressive.
- Creatinine: A waste product of muscle metabolism that is removed via the kidneys. The level of creatinine in the blood (serum or plasma) has
- commonly been used to assess kidney function, but a formula-based estimation of the glomerular filtration rate (see entry) is more accurate.
- Demographic: Relating to the characteristics or composition of a population
  Diabetes: A group of disorders in which the normal insulin mechanism fails so that glucose in food cannot be metabolised, and builds up in the blood. Over time raised blood glucose causes damage to blood vessels, including those in the kidney, causing cardiovascular disease and loss of kidney function.
- Dialysis: A blood purifying treatment in which waste products and excess water are filtered out of a patient's blood artificially. It is used when the patient's kidneys no longer function sufficiently to maintain life (see haemodialysis and peritoneal dialysis).
- End Stage Renal Failure: Another name for established renal failure (see entry)
- Established renal failure (ERF): Established renal failure (ERF), also called End Stage Renal Failure, is chronic kidney disease which has progressed so far that the patient's kidneys no longer function sufficiently to maintain life.
- Functional capacity: The extent to which someone is able to carry out normal activity
- Glomerular filtration rate: The rate at which the glomeruli in the kidneys excrete waste products and excess fluid. It reflects the percentage of normal filtration function remaining. Formulae for calculating estimated GFR take into account factors such as the patient's age, body mass and ethnic origin
- Haemodialysis: A blood purifying treatment in which the patient's blood is circulated through a machine drawing out waste products by diffusion and excess water through a filter. In ERF this is normally done for around four hours, three times weekly, usually in a hospital or satellite unit.
- Heartbeating donor: A person who has died while still on a ventilator in a critical care unit. The circulation is maintained until the organs are taken for transplantation.
- Living donor: Someone who donates a kidney when they are alive. A single kidney is enough to maintain health, so one can be donated for transplantation.
- Non-heartbeating donor: Normally a person who has died in hospital following a cardio-respiratory arrest. If steps are taken immediately to retrieve or preserve organs they can be used for transplantation.
- Pathology: A branch of medicine which studies the causes and nature of diseases, including changes in body tissues and organs which cause or are caused by disease
- Peritoneal dialysis: A form of dialysis in which dialysis fluid is introduced into the peritoneal cavity in the patient's abdomen, where it draws waste products and excess water out of the blood using the peritoneal membrane as a filter. The fluid may be exchanged four or five times per day, or a machine may be used to carry out several fluid exchanges, usually overnight.

- Renal replacement therapy (RRT): Treatment to augment or replace the function of failing kidneys, by dialysis (peritoneal dialysis or haemodialysis) or transplantation
- Satellite unit: A unit providing haemodialysis, and sometimes other services, linked to a main unit which provides a full range of services. Usually it provides treatment for more stable patients, closer to where they live than the main unit.

Appendix C:
Literature Review Records

Search Results for Literature Review

Medline

To Review	10
Staff	2
Fluid Adherence only	5
Diet adherence only	5
Fluid & Diet adherence	2
Medication	3
Paediatric Paper	7
Transplant Paper	2
Main focus outside renal	12
Medication and diet	1
Meds/diet/fluid	1
Older than 2000	11
No consideration of the psychological factors	4
Review Paper	2
Total	**67**

CINHAL

To Review	1
Staff	0
Fluid Adherence only	3
Diet adherence only	2
Fluid & Diet adherence	0
Medication	1
Paediatric Paper	1
Transplant Paper	0
Main focus outside renal	5
Older than 2000	0
Med/transplant	1
No consideration of the psychological factors	1
Review Paper	0
Total	**15**

PSYCHINFO

To Review	5
Staff	1
Fluid Adherence only	2
Diet adherence only	1
Fluid & Diet adherence	1
Medication	0
Paediatric Paper	1
Transplant Paper	0
Main focus outside renal	8
Medication/transplant	1
Neurology Paper	1
Medication and diet	1
Older than 2000	3
No consideration of the psychological factors	6
Review Papers	0
Total	**31**

WoK

To Review	3
Staff	1
Fluid Adherence only	4
Diet adherence only	8
Fluid & Diet adherence	2
Medication	3
Paediatric Paper	6
Transplant Paper	0
Main focus outside renal	13
Medication/transplant	1
Paper unavailable	2
Older than 2000	10
No consideration of the psychological factors	7
Review Papers	3
Total	**63**

Combined Records

Total for selected databases (after exclusions)	19
Minus duplicates	11
Added after citation search	12
Total Number of papers included in Review	**12**

Appendix D:
Summary Table of Past Qualitative Renal Research

Review of identified themes in qualitative research into renal dialysis patients

Themes identified in qualitative renal dialysis research	Details of papers of identified theme
Adjustment/ Identity	Faber, Castell & Bryson (2003) Gregory, Way, Hutchinson, Barrett & Parfrey (1998) King, Carroll, Newton & Dornan (2002)* Tong, Sainsbury, Chadban, Walker, Harris, Carter, Hall, Hawley & Craig (2009)
Independence./Dependence	Gregory et al. (1998) Lindquist, Carlsson & Sjöden (2000) Molzahn, Bruce & Shields (2008)
Living/ Not living	Al-Arabi (2006) Hagren, Petersen, Severinsson, Lűzen & Clyne (2005) Molzahn et al. (2008) Tong et al. (2009)
Restriction/ Control	Al-Arabi (2006) Hagren et al. (2005) Lindquist et al. (2000) Martin-McDonald & Biernoff (2002) Molzahn et al. (2008) Tong et al. (2009)
Losses	Faber et al. (2003)
Isolation/emotional distance	Faber et al. (2003) Hagren et al. (2005) Martin-McDonald & Biernoff (2002) Molzahn et al. (2008)
Coping	Hagren et al. (2005) King et al. (2002)*
Quality of Life (QoL)	Al-Arabi (2006)

Normal/Not normal	Lindquist, Carlsson & Sjöden (2000) Molzahn et al. (2008)
Uncertainty	Gregory, et al. (1998) King et al. (2002)*
Impact of family/care givers	Gregory et al. (1998) Tong et al. (2009)

** Sample pre-dialysis (low kidney function) patients and dialysis patients*

Figure 1 gives an overview of qualitative research on renal dialysis patients and the emergent themes; this table is not intended as an exhaustive review of the literature. Qualitative studies on renal failure were examined and the main themes tabulated as presented in the results section.

Appendix E:
Interview Schedule

18/02/2010 Version 1

Schedule (1) adapted from Smith and Osborn, 2008

Date:

Start Time:

End Time:

Main Interview

1. Introduce myself and my research ☐
2. Ensure that the information sheet has been read and understood ☐
3. Summarise interview schedule and IPA style ☐
4. Any questions at this stage? ☐

   If yes, document: _____

   _____

5. Explain and sign consent form (give copy to participant) ☐
6. Complete front page, demographic information ☐

A. Dialysis

Question 1: Could you describe for me what happens in dialysis in your own words?

Question 2: What do you do when you're having dialysis?

Question 3 : How do you feel when you are dialyzing?
Prompt: physically, emotionally, mentally

Question 4: How do you feel about having dialysis?
Prompt: relief/ inconvenience as examples.

Question 5: If you had to describe what the dialysis machine means to you what would you say?

B. Identity

Question 6: How would you describe yourself as a person?

Question 7: Has having kidney disease and starting dialysis made a difference to how you see yourself?

Questions 8: What about before your diagnosis?

Question 9: How about how others see you?

C. Coping

Question 10: What does the term illness mean to you, how would you define it?

Question 11: Do you see yourself as being ill?
Prompt: sometimes, always. Would you describe yourself as 'ill' to others?

Question 12: On a day-to-day basis, how do you deal with having kidney disease?
Prompt: strategies – practically/ emotionally

Question 13: Do you think about the future much?

D. Unstructured interview time

Question 5: Do you have any further comments about this issue that we have not already discussed?

Allow time to explore ideas that are raised.

Appendix F:
Recruitment Details & Flow Chart

18/02/2010

Recruitment and Research Procedure – written description

- Consultant Nephrologists were approached by the research supervisor and asked to provide 3-4 possible candidates to be approached for the research. Once individuals were identified, in line with the inclusion criteria, the researcher will liaise with the renal team to be in attendance at the next outpatient appointment that the suggested participants are attending.

- Prior to this appointment potential participants received a participant information sheet and a covering letter allowing them to consider their involvement.

- On attending the clinic the Consultant Nephrologists or Clinical Nurse Specialists received feedback from individuals on whether they wish to be involved in the study. If there are interested the researcher will then be introduced to the potential participant.

- The researcher then further introduced the research to the individual following and used this opportunity offer further information regarding the study and to discuss consent and confidentiality and organise the research interview if the individual was still willing.

- Semi-structured interviews were conducted with participants. These lasted between 40- 60 minutes. Interviews were typically completed prior or following the haemodialysis treatment. For safety and insurance reasons interviews were conducted on NHS sites.

- Prior to the main interview, participants were be briefed on confidentiality, if they have received adequate information regarding the study, the reason for the recording of the interview and given an opportunity to ask any questions.

18/02/2010

- Once the briefing is completed participants were given a consent form to complete to say they have agreed to be interviewed, recorded and for the transcript to be analysed and that they have received adequate information regarding the study. An opportunity to read the consent and ask questions was then provided.

- Demographic data was collected as standard from each participant. This will be collected on a standard form.

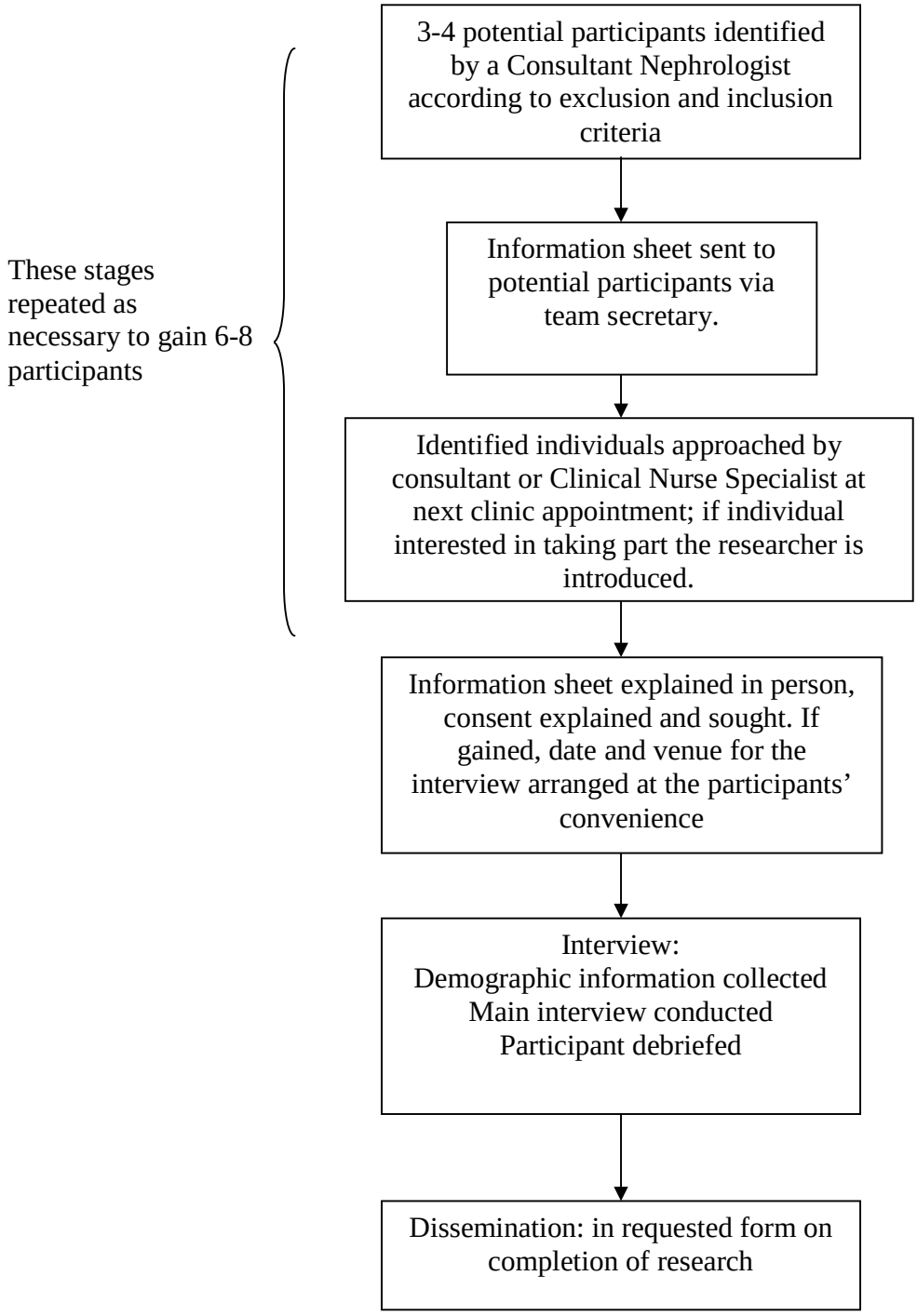
- Participants were interviewed using a semi-structured approach..

- Participants were given the opportunity to ask further questions or share any concerns about taking part in the study. The researcher debriefed the participant and provided contact details and advice regarding how to proceed if they become distressed by any part of the interview procedure (Renal Clinical Psychologist).

- Following the interview a brief letter was sent to the G.P., through the team secretary, to inform them that the individual is involved in the research; consent for this is part on the consent form.

18/02/2010

Flow Chart of Recruitment and Research Process



Appendix G:
Participant related information

-Participant information sheet
- Covering letter for information sheet
-Consent form
-G.P. letter
-Demographic information sheet

Participation Information Sheet

Study Title: The Experience of Men with a Diagnosis of End stage Renal Failure receiving Hospital based Haemodialysis

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve. **One of our team will go through the information sheet with you and answer any questions you have.** .We'd suggest this should take about 5-10 minutes Talk to others about the study if you wish. Ask us if there is anything that is not clear. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?
The purpose of this study is to gain an understanding of individuals' experiences of having a diagnosis of renal failure and of being treated by haemodialysis.

Why have I been approached?
For the purposes of the study we need to recruit a small number of adult men who currently have a diagnosis of End Stage Renal Failure currently undergoing hospital based haemodiaysis. You have been suggested by the renal care team as meeting these criteria and sent this information sheet to consider whether you might like to take part.

Do I have to take part?
No. It is entirely up to you to decide whether or not to take part in the research. Following being given information about the research, if you decide to take part, you will be asked to sign a consent form indicating that you understand the project and have been given the opportunity to ask any questions that you may have. If you do decide to participate, you are still free to withdraw at any time, without giving a reason. If you change your mind about participating in the study at any time contact the researcher by email or leaving a message with the renal team psychologist and all your data will be withdrawn from the study and destroyed. There are no consequences to deciding not to take part.

What will happen if I take part?
If you decide that you would like to participate in the research, please communicate this to your consultant at your next clinic appointment, who will be aware you have received this information sheet. You will then have an opportunity to meet with the researcher, go through the information sheet and ask any questions. If you are still willing to take part consent will then be discussed and recorded in writing (you will be asked to sign a form) also a letter will be sent to your G.P. to inform them that you are taking part in this study; no further information will be shared. We will arrange a suitable time to conduct the research interview; this interview will most likely be at your usual treatment site and I will be as flexible as possible in offering you an appointment that suits you. The interview is about understanding your experiences of diagnosis and treatment. This interview will last approximately 1 hour; the interview will be recorded for the purpose of the study. This is the only occasion you are required to meet the researcher. You will be asked if you would like to receive feedback on the outcome of the study and how you would like to receive this information. The study will run from spring 2010 until summer 2011 when all write-up will be complete, participants will receive feedback on the completion of the write-up process.

What are the possible disadvantages and advantages of taking part?
It is important to state that there may be no individual benefit to taking part in the research, but it is hoped the findings of the project will be useful to those working in, and receiving care from, renal services, including those operating through University Hospital Coventry and Warwickshire NHS Trust.

There is the possibility that the interview may bring up topics that are upsetting or distressing for you. You do not have to answer any questions that you would prefer not to. On completion of the interview there will be time to discuss any questions you may have and the researcher will advice you about what to do if you have felt distressed, or become distressed, about any subject matter discussed in the interview.

Will my taking part in this study be kept confidential?
All information that is collected from you during the course of the research will be kept strictly confidential with all contact details, interview notes, transcripts, questionnaires and other paper and electronic documentation being kept securely either in identified locked cupboards or under password control encrypted files.

Names and other identifying features will be obscured or changed in the reporting of the work in order to protect your privacy. Your name will not be used in any reports or outputs. Any reference to names and places will be disguised. All data will be kept according to the Data Protection Act 1998.

The only exception to this is if you identify that you are at risk during the interview, in these circumstances it may become our professional duty to involve other parties. This will be discussed with you should this occur.

Also, if during the interview you disclose any criminal activities these will have to be disclosed with the relevant authorities.

What will happen to the results of the research study?
You will be given the option of receiving feedback on the outcome of the research on completion; this is likely to be summer 2011. The final anonymised report may be published in journals aimed at health professionals and academics.

Who is organising the research?
The research is being organised by Hannah Seabrook (Trainee Clinical Psychologist). The research is registered with Coventry University and is in co-operation with University Hospitals Coventry and Warwickshire NHS Trust.

Who has reviewed the study?
This research has been reviewed and approved by the Coventry University ethics board. Additionally, all research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Coventry University Ethics Committee and the University Hospitals Coventry and Warwickshire NHS Trust Research and Development Team.

What if I have any further questions?:

Contact for Further Information

Hannah Seabrook Clinical Psychologist in training Clinical Psychology Doctorate Course James Starley Building Coventry University Priory Street Coventry CV1 5FB. Tel: 02476 968 290 (Please leave a message) Email: seabrooh@coventry.ac.uk	**Dr Julie Highfield** Clinical Psychologist Renal Unit, Level 5 East Wing, University Hospital Coventry and Warwickshire NHS Trust, Walsgrave Site, Coventry, CV2 2DX. Tel: 02476 968 290 (Secretary: Louise Ford)

If you would like independent advice regarding taking part in research please contact the Patient Liaison Service (PALS) on 0800 028 4203

18/02/2010 Version 1

Dear

We would like to invite you to take part in some research currently being undertaken at the Renal Unit.

Please find enclosed a detailed 'Participant Information Sheet' that will explain the process of being involved in the research, why the research is being done, why you have been approached and what it would involve. This will help you to decide if you wish to take part. Taking part is voluntary, and choosing not to take part will not have any impact upon your medical care from the Renal Unit.

Please feedback to the team at your next out patient appointment about whether you would like to speak to me about being involved in this project. The researcher will be available in the reception area of your next outpatients appointment to discuss the research further, should you choose to consider participation.

I would like to thank you for taking the time to read this letter.

Yours sincerely,

Hannah Seabrook **Trainee Clinical Psychologist/ Chief Investigator**

Under the supervision of:

Dr Julie Highfield **Clinical Psychologist (Clinical Supervisor, UHCW)**
Dr Adrian Neal **Clinical Psychologist (Academic Supervisor, Coventry University)**

Title of Project: Men's experiences of hospital based haemodialysis in End Stage Renal Failure

Name of Researcher:

Participant Name: Participant Code:

Please initial box

I confirm that I have read and understand the information sheet for this study and have had the opportunity to ask questions.	☐
By handing this form back to the researcher I am giving my consent for my data to be used in this research study	☐
I understand that my participation is voluntary and that I am free to withdraw consent at any time, without giving any reason, without my medical care or legal rights, or those of the person I am giving consent for, being affected.	☐
I understand that the interview will be audio-recorded for the purposes of transcription and held this format for no longer than 48 hours, then erased.	☐
I agree to my GP being informed of my participation in the study.	☐
I consent to take part in this research	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Dear

This letter is to inform you that your patient _____ has recently consented to take part in research being conducted within the renal care team. The title of this research is:

'The Experience of Men with a Diagnosis of End stage Renal Failure receiving Hospital based Haemodialysis'.

They have consented for you to be informed of this. If you are interested in this research or require any further details please to not hesitate to contact me.

Yours sincerely,

Hannah Seabrook **Trainee Clinical Psychologist/ Chief Investigator**

Under the supervision of:

Dr Julie Highfield **Clinical Psychologist (Clinical Supervisor)**
Dr Adrian Neal **Clinical Psychologist (Academic Supervisor)**

Demographic Information

Strictly Confidential

Date:

Participant Identification Code:

Date of Birth:

Date of diagnosis of End Stage Renal Failure:

Length of time on haemodialysis:

Dialysis site

School Leaving Age

Employment/ Occupation

Appendix H:
Ethics

- Coventry University Ethics
- Birmingham, East, North and Solihull Research Ethics Committee on behalf of the NHS National Research Ethic Committee
- NHS Research and Development, UHCW NHS Trust

TO WHOM IT MAY CONCERN RRU/Ethics/Sponsorlet

02 May 2011

Dear Sir/Madam

Researcher's name: Ms Hannah Seabrook
Project Title: Men's experiences of hospital based haemodialysis in End Stage Renal Failure

The above named student has successfully completed the Coventry University Ethical Approval process for her project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this student and attach details of our Public Liability Insurance documentation.

With kind regards

Yours faithfully

Professor Ian Marshall
Pro-Vice-Chancellor, Research

Enc

University Hospitals
Coventry and Warwickshire
NHS Trust

Research & Development Department
R&D Services Manager: Ceri Jones - Tel: 024 7696 6196
R&D Divisional Finance Manager: Chris Moore - Tel: 024 7696 6198
Deputy Divisional Finance Manager: Reena Savani - Tel: 024 7696 6197
Assistant Research & Development Manager: Natasha Wileman - Tel: 02476 966197
Research & Development Assistant: Isabella Petrie - Tel: 02476 966202
Research & Development Assistant: Claire Bacon - Tel: 02476 964495
Post Doctoral Research Grant Writer: Deborah Griggs - Tel: 02476 96 6195

University Hospital
Clifford Bridge Road
Walsgrave
Coventry
CV2 2DX

Tel: 024 7696 4000
Fax: 024 7696 6056
www.uhcw.nhs.uk

23rd September 2010

Our Reference: JH075410
MREC number: 10/H1206/43

Miss Hannah Seabrook
Trainee Clinical Psychologist
Coventry & Warwickshire Partnership Trust
St Michael's Hospital
St Michael's Road
Warwick, CV34 5QW

Dear Hannah,

Study Title: Men's Experiences of Hospital based Haemodialysis in End Stage Renal Failure.

Thank you for submitting the above study for consideration by the Research & Development Office, in line with new regulations governing R&D approval of local sites from 1st April 2009. I am pleased to inform you that the study has been approved. For reference, the approval number is: JH075410 and it would be appreciated if you could quote the R&D reference in all future correspondence.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D Approval assumes that you have read and understand the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

The Trust wishes you every success with your project.

Yours sincerely

pp

Ceri Jones
Research and Development Services Manager

Cc: Natasha Wileman, R&D Assistant Manager, University Hospital
Julie Highfield, Clinical Psychologist, University Hospital

NHS
National Research Ethics Service
Birmingham, East, North and Solihull Research Ethics Committee
REC Offices
Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW
Telephone: 01527582532
Facsimile: 01527 582540

10 August 2010

Miss Hannah Seabrook
Trainee Clinical Psychologist
Coventry and Warwickshire NHS Partnership Trust
St Michael's Hospital
St Michael's Road
Warwick
CV34 5QW

Dear Miss Seabrook

Study Title: **Men's experiences of hospital based haemodialysis in End Stage Renal Failure**
REC reference number: **10/H1206/43**

Thank you for your letter of 04 August 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV		
Protocol	2	05 March 2010
Demographic Information	1	18 February 2010
Experience of key investigator/collaborator		10 May 2010
Insurance document from Coventry University		01 July 2010
REC application	2.5	10 May 2010
Covering Letter		
Summary/Synopsis	1	18 March 2010
Letter from Sponsor		07 May 2010
Interview Schedules/Topic Guides	1	18 February 2010
Letter of invitation to participant	1	18 March 2010
GP/Consultant Information Sheets	1	18 February 2010
Participant Information Sheet	2	01 July 2010
Response to Request for Further Information		
Participant Consent Form	3	01 July 2010
Summary CV for supervisor		10 May 2010
Evidence of insurance or indemnity		10 May 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1206/43	**Please quote this number on all correspondence**

Yours sincerely

Dr Rex J Polson
Chair

Enclosures: "After ethical review – guidance for researchers" SL- AR2

Copy to: Dr Julie Highfield
Renal Services UHCW
5th Floor East Wing
Clifford Bridge Road
Coventry
CV2 2DX

Appendix I:
IPA Analysis

- Master themes with supporting quotes
- Pages of annotated transcript

Master Themes with Quotes

The many sides of the HD treatment experience	The burden of HD	Tom: Then...you, I tend to struggle towards the end of it because you have a bad head or you feel rough or...or you just feel drained so I just switch it off and do what I possibly can as long as I can keep my self-occupied I've found it's better for me Tom: Awful (laughs) …process. Takes your blood out...er…purifies it and takes the fluid out and just returns it back to your body...that's the basics of it really…um… I don't know what else to say Tom: But I think most of the time 90% of the time, even 95% of the time you just feel rough. When you come off you seem to like… tend to go down, what I mean by that is… um… you tend to feel worse, I tend to feel worse for the first 6-8 hours then I pick up again and that's how I tend to do it...I hate it, I hate every moment of it… Tom: If you compared it with a figure such as... the president of America and a dialysis machine, they're about on par, yeah ok you don't like politicians, I don't anyway I just don't like what it stands for like politicians stand for the country the work, whatever, dialysis machine stands for my life and I don't like that. It's...er…evil...it's just scary Sandeep: Er…I used to be very tough, like, you know mentally and physically like but er …I've been through quite a bit with the dialysis…you know…er...had 2 transplants they've failed, I've had the kidneys taken out, had one of my own kidneys taken out…had er..a tumor out due to the drugs I was taking, cyclosporine...so yeah had a tumor out, radiotherapy so er it's soft end me a lot really, I'm not as tough as I used to be… Sandeep: You just...it does keep you alive...er...that's it basically I…I don't think it a quality…you're not getting a quality still...there's no quality there...you're going on alive breathing but you can't enjoy your food, can't eat what you want to eat…you can't drink certain things...or a bit too much to drink one day cos you don't pass er…you're not passing any urine like so you know it's...yeah, it's a struggle basically, it's a struggle. Sandeep: basically it keeps you alive but with me it just wears me right out makes me feel really bad but it keeps me alive basically Sandeep: Well it keeps me alive basically...without that I'm finished really so…er you need it but its harsh, it's very harsh and some days you think oh Christ but you you've got to plod on with it…that's it really… Sandeep: And then you wake up next day sort of thing or in the night and get round it…it affect you….it affects you, there's no get away from it there's such a thing as good dialysis Sandeep: It's not just being here it's all the things that come with it and they haven't really made advances as such big advances really there the EPS and that's a little bit better not as harsh…very poor quality of life always tired always worn-out my bones are crumbling now I get a lot of pain in my arm my whole bodies worn out basically

		Mark: I had more energy and it's all to do with… organisation… you've got to organise yourself. Dialysis treatment's like going to work… that's how I get my head around it. I make myself a packed lunch I make myself a flask and I'm going to work for 6 hours that's how I get my head around it.. if some things got to be done do it, get on with it Mark: Er… wouldn't say I was 100% on dialysis because I don't think anyone could… it's not the sort of live anyone would want… John: Yeah physically, you just feel horrible you heads a little bit fuzzy and you just don't feel right and then when you do actually go low it just like one of these things where you just go low and you get sick and things like that which you don't want to do and erm (sigh)…so you kind of worry about that thing going on John: Er…I'm all right towards the end of it er… er… i… you kind of …you start feeling a little bit...I've got bad… high blood pressure anyway but when you come to the end, depending on how much weight you're taking off you kind of …erm… you're sitting there and your thinking ahh, you want it to finish John: Cos you may have known renal patients, you may have spoke to some and they can moan…and they're quite good at it as so you don't want to hear them all the time you want to hear the good, so you have a chat with the girls, you don't want to be listening to moaning all the time, especially when you're out there Niraj: If something goes wrong I don't panic I look at how we can sort it out so yeah, yeah not too bad... Generally, the odd times when I'm not well, you go low or your blood pressure drops or whatever then… erm you know you have to deal with it basically and you can feel a bit spaced out then for a little while afterwards so… Niraj: I can't not view he dialysis machine as something which er… as you know negatively at all you know it's a positive thing that's there to keep us alive and health and er… and you used the word relationship, I suppose if you want to talk relationships it's on the whole good but like any relationships you know you have your moments Niraj: … you know mentally you just don't feel as sharp as you did before and I think that's a lot to do with dialysis and people don't look at that aspect… the affect on the mental stimulation some patients will carry on for a while and they… Niraj: Niraj …since I've been on haemodialysis, since I've not been able to function and work as, as, as much as I used to that has slowed and I hate that that's the most frustrating aspect… I worry it'll continue… I don't want to be a doddering old git Peter: Erm… I feel… I mean it's hard to say because every day's different when you're on it. I mean the majority of the time when I'm on it I feel like I'm hot and sweaty and… tired…. Peter: then they stick 2 giant needles in your arm (laughs) which are quite painful… er… then after they've stuck the 2 of them in, they basically hook you up to the machine…

		Peter: So that's how it's disrupting your life, you can't lead a normal-ish life. You can only do certain aspects I mean you can't… you can't like, you can't do sports and that because the tiredness will get a lot of people… Peter:
	Support within the renal community	John: Yeah, oh god yeah they're important because it be a horrible place otherwise. Cos you may have known renal patients, you may have spoke to some and they can moan…and they're quite good at it as so you don't want to hear them all the time you want to hear the good, so you have a chat with the girls, you don't want to be listening to moaning all the time, especially when you're out there (points toward unit). (Laughing) John: Erm...sometimes er I'll talk with the staff which is always good 'cos the day goes along or the 6 of us will normally have a chat as well so it all depends how the day feels. Tom: …you get people on dialysis you get friendly with and the worse scenario is they die and that is one of the bad, bad ways you change because you think that could happen to me one day but I think every aspect of it makes you change… Tom: I've know I think it's about 6 people who I've been close to who we've lost over the past couple of years and that is it's scary but it either hardens you or make you think…yeah…I find that very unsettling in that sense Peter: it's just like as soon I walk through the door onto the unit it's like oh here I am again and it's just one of them, but you come in at the same time with the same team with the same people, unless you change your team, it's the same people so you have conversations with then which passes the time and you say, oh I'm not feeling very good today I'm feeling this, I'm feeling that 9 times out of 10 they're in the same boat or they've been in the same boat as you so they know how you're feeling Naraj: Luckily the team I'm in's quite good similar age group similar level…men… mental level really so we all have a laugh and a joke, we're probably the noisiest team in the unit so yeah it's quite good. Niraj: Oh it makes the time go much, much quicker and actually you don't… resent looking…. Looking to come it to dialysis it actually becomes another part of your social circle so that takes some of the edge off while you're there… so it makes it more bearable. Mark: That support is very important to me. Because even though I've got to meet a lot of people here and even though I've moved from one ward to another ward I've still been put on a ward where I know a couple of people and we're still in the same frame of mind… so I'm still alright that's why I'm still on a high… because I've still got people around me where I enjoy their company… so to speak… and they don't pull you down… and they don't moan (laughs). Mark: And other patients want to talk to you…I've been lucky because I've been on a ward where other patients really want to talk to you and their in my sort of age… and a similar sort of sense of humour so they sort of brought me out…out of it…like answering questions that me or my wife would ask…but it took a long time for me to… settle in .

		Mark: but my wife and a couple of other patients, their wives.. cos we sort of get together every now and then and we talk about this. They're all going through the same thing…and it's a lot of pressure on the wife because they see their husband just gone… and all of a sudden it's a different person to the person they've married. Sandeep: I don't really I don't really talk about my illness unless they've got a problem with, you know, their health and then, sometimes I'd say yeah I've got a problem like to the others on dialysis at the hospital… otherwise I don't really discuss it with Sandeep: I've known people like that it the past who you know they've had enough they just don't care and they put a tube in the chest… back in the days when you dialysed in the 80s people were popping off all the time. To see people you know go…that's hard.
	Emotional Impact: 'It's very difficult'	Tom: um you feel helpless…hopeless. Gets you down depressed, you handle it the best possibly way you can. Tom: During the first few years I should imagine, when I say few years the first 6-7 years, something like that it was horrendous you just didn't want to go in you didn't want to sit there for the time period you felt awful you wasn't rough or whatever.. you just felt...i felt a helplessness in a small way Tom: you can feel drained you can feel physically tired, your body can ache, you just...um...I'd even say emotionally upset as well because you know you know you don't particularly want to be there but you just tend to take it the way have it the way you've learnt to take it sort of thing Sandeep: Now I'm very emotional now I never used to be an emotional person. I used to be fair you know but I was mentally quite tough...but now…the little things upset me…mmm Sandeep: Er…I used to be very tough, like, you know mentally and physically like but er …I've been through quite a bit with the dialysis…you know… John: Oh I'm fine I just I'm just like any other time when we just sit there and we talk and you know John: (Laughs) I don't think there is one, personally [*an emotional side to coping*] I don't think there is...erm...the funny thing is, I'm not really fussed about, I know this sounds really stupid, I don't know if this sounds really stupid but I'm not really fussed about me. I'm more fussed about me family among as me family are all right, me mum, me sister, my little brother my other brother who live everywhere else and me nieces and nephews as long as there alright, yeah, I can kind of say I'm doing this everything's good so I' more bothered about them than I am about me Mark: For me that's my own personal opinion…. there was a bit of guilt (sigh) there about going in sitting down and costing a lot of money... so there was guilt there… at least this way I've got a little bit of…how can you put it… er… I'm giving a little bit back so to speak taking a bit of pressure off…off the system if that's possible..

		Mark: Depressed was… would be a good word to describe it at the beginning…er… quiet, withdrawn…didn't really want to talk to people Mark: but this illness… that's why it hit us hardest because we thought we had a second chance and it just got took away from us…but we got through it, we're getting through it and it's been hard, it still going to be hard but… the only thing I can say is just keep going er… Naraj: But there is always that part of me that… knows what I was... and what could have been so yeah, that's always there Niraj: if I put my mind to it I can do most thing I suppose some of that has gone you know because I'm vulnerable and don't like being vulnerable I'm reliant on something to keep me going… I'm never sure whether I'm going to have the energy or not to do something so you do become a little bit vulnerable and you do become I little bit less confident because of that. Peter: … so I feel really bad when I walk through the doors. But it's just one of them… you have a lot of emotions about it but there's not set thing in your mind about it some days you don't want to do it you feel as though you don't need it Peter: Yeah, yeah, I mean... before erm... yeah I mean I wasn't.. I wasn't depressed, or as depressed, as what I am now. I mean when you're going on, when you're on renal dialysis you just feel like you're just erm… how can I put it… you feel like the whole world is against you Peter: Erm…. I think about the future more now that I did 6 month ago… 6 months ago I was… very… depressed… I didn't want to do dialysis anymore I didn't want to… live basically
Coping the best way you can	How did I get here?	Sandeep: Your bodies just weak… you're weak. I can't lift a can't pick up my children…it's really...it's bad...you're fighting all the time…it's a fight all the time...that's all…yeah…that's all Sandeep: .it is a lot…it's punishing basically it's punishing. It's not just being here it's all the things that come with it and they haven't really made advances as such big advances really there the EPS and that's a little bit better not as harsh…very poor quality of life Tom: If you compared it with a figure such as... the president of America and a dialysis machine, they're about on par, yeah ok you don't like politicians, I don't anyway I just don't like what it stands for like politicians stand for the country the work, whatever, dialysis machine stands for my life and I don't like that. It's...er…evil...it's just scary Tom: Oh yeah, big time I lost my marriage and everything because of it John: before I used to go out used to go to the pub or go down the golf course…play a bit of gold whereas now because of that time I'm not really fussed about what's going on now you I just accept it it's the way things are…and that's me lot…

		John: Again going back to those 18 month ago it doesn't bother me because I've got so use to being stuck indoors and not being able to do anything for myself that in...that in my head it's just its… it's one of them it's just tough, tough cookie Naraj: It's part of life… that's it, yeah, yeah, probably drew a shorter straw that some people... yeah… but have I made the best of what I've got … yes you know so I don't let it get me down to much but obviously the things… the things that other people take for granted I... I… I, I, I can't…and when I see normal healthy people that don't do anything with their life's that's er… that angers me Niraj: This… it's just one of those things… Sandeep: Yeah, yeah I mean you appreciate er… basically you're lucky to be here basically getting treatment but also how others feel, you I know worse off than you so in that way I appreciate that and think you should be grateful for the little we get. Sandeep: Yeah I was very outgoing, very tough, I used to train a lot… you know, kept my body in good shape…very, very fit…I did martial arts, did boxing, did weight training…didn't smoke, didn't drink, had a good diet and everything so it was a big shock that you know one day I had a bit of a temperature and er within 2 days I was in hospital and that was the end of that… Tom: Wife at the time kicked me out. Tried to stop me from seeing my daughter. Called the police every time I tried to get access to me daughter. 'Yes you can see your daughter' the next minute the police were there. It just went on and on. It just messed me , messed me up so much in my head it was unreal John: No, it was really weird because when I came in again everything was just going so wrong (sigh) I had no idea I had renal failure whatsoever I came I with a er...a very low blood count and the Dr that seen me send me for a blood test on the Friday and er… that Friday night he rings me up and goes you've got to go to hospital so I come straight to hospital and I don't know anything about it whatsoever I just that I was unhealthy and they tested me and they said oh… we'll give you a bit of iron and then hopefully you know…you can go home the next day and I was went oh well that's fair enough…that's not too bad and then they came back later on and went your kidneys don't work and I said oh and they just the way I thought about it was just that's another thing wrong with me and er… that was the way a thought about it oh you know ok that's what's wrong with me…and so in a way it was probably a blessing that they knew… Mark: Because I felt like why me… why should I be here I'm only 50… why should I be here? Why me? Er… taken out of the system the way I have been… cos I've always worked and I love my job..er…and I resented the disease. Peter: …yeah…yeah I mean I would say that I see myself as someone who is being punished… for… how I am erm… I've not brought this on myself or anything like that and then I'm being punished, I mean I've never been a religious person or anything like that so I'm not going to sit here and say I'm being punished by god for whatever I've done… so I just feel like I'm being punished but I've never done anything to be punished… I never done anything to make me be punished for... like I've never

		taken any drugs or anything like that that would have caused all this to happen er… it's just of those things that's happened to me. My mum feels it's her fault but I've not blamed her, I've not had any arguments with her about it or anything like that, I know how hard she takes it. So... I can't be angry at my mum, it's not her fault, she sees it as her fault for how I am, bit I refuse to blame her for my problems.
	Finding a way through it	Tom: Take each day as it comes. If you feel ok do what you can do, whether it's shopping visiting friends, tidying your house internet, going out meeting friends or whatever and the opposite is if you don't do well, you don't do anything you go to bed… Tom: I think it's that big word control. If you can control your life you tend to feel better about it... this way…over the years from when I was first poorly...diagnosed with this I was like a scared lion I suppose I'm not quite a pussy cat now but I'm something I can.. accept it I just live with it Tom: When I come for my dialysis I do what I have to do. I'll be pleasant to nurses, other staff, other patients but when it's my time to go home I just want to go home…just go Tom: Take me daughter away and I'd jump off the roof. … My daughters everything to me, if it wasn't for my daughter I'd have no reason. Sandeep: Well I've got no choice really, I've got kids so… its… so… err… you know can't just sit in bed, like you know I don't feel like getting up but I get myself up and I get on with it…you know Sandeep: I get myself up and I get on with it…you know John: I know you, I know it sounds very hippyish but you go with it if you just allow it to happen, you do your four hours, you don't moan about it alright you can moan all you want but… and then you come off it you go home you have your cup of tea you have your drink and all that and…life's alright. John: Erm I read papers, er (sigh) probably sounds dreadful but I read papers, I'll read papers, I read a book, I watch a bit of telly I mainly stay in John: I've got to be honest I poke fun about being a man on dialysis because of things (suggestive face) don't work and err… I just poke fun at all that whole business cos… I don't take it seriously, I mean as I said I don't pass fluid I don't do anything whatsoever and it's just hilarious when you hear people having to go to the loo and you think ha I don't do that… John: No (laughs) I thing that's about it. I know it sounds really stupid but try and enjoy it… that all Mark: And it took a long time for me to get my head round it. If you'd asked me 4 months ago if I'd be doing self care I'd have laughed at you and said no chance… but in that period of time I realised that I can do stuff for myself… I can get on with

		it and life doesn't have to be… that bad. Mark: Now it's different because I'm taking control… I'm taking control of my actual care Mark: And it's…er…it's er… different for everybody cos I've talked to other patients and they've all got their own little story to tell…but er… for me personally doing it for myself and learning… I wouldn't call it a skill but… something like that… is quite an achievement for me and to be able to do it for myself Mark: … because I'm coming out of it.. I do try… er… I do try and look on a positive side like if there's any trials... if there are any trials going on anything I can do to help anyone... I will go on these trials and I will, like this, I will do it without any qualms, doesn't matter what it involves… I… I'm the sort of person… I'm not a clever person but if I could pass on anything that could help anyone else Mark: Dialysis treatment's like going to work… that's how I get my head around it. I make myself a packed lunch I make myself a flask and I'm going to work for 6 hours that's how I get my head around it.. if some things got to be done do it, get on with it Mark: You've got to be positive… you can't be positive all the time but I would say you need help you need people around you who knows the disease, who knows what you're going through…. To talk to people is the best way around it I've found. Don't try and withdraw yourself in and cope with it on your own because you just won't do it…. I don't think you will… I mean some people can but there a special breed… but me I would have never of done it without the people around me. Niraj: Firstly… you've got to stay positive, you've got to have a positive mental attitude it's, it's, it's… it's an issue when you start don't let the condition… don't live for the condition… live for… no… let the condition let the treatment help you live the rest of whatever you've got left er… I've phrased that really badly actually what I actually what I mean really is er… don't live to dialyse, dialyse to live… Naraj: Ok… um… secondly… as much as, you know…as much as you think you know you think you're going to carry on as you were you got to look at what limitations you have and then once you've looked at the limitation don't focus on what you can't do find things that you can do… Niraj: you know here am I wanting to do things and not getting the opportunities… not getting the opportunities simply because of my health… so er… yeah I think you have to sort of push those thoughts aside to a certain extent I know in your private moments… you can kind of think, well ok, but what the hell Niraj: Er… yeah absolutely erm… initially you use dot get a lot of pity and sympathy which I would just shun, not interested not your problem, my problem I'll deal with it so… er… now they accept ok not to… give me that Peter: actually if I was truthful about it I bloody love the thing because it's keeping me alive… not like 50-60 years ago when there was nothing…there was no machines and people just dies a horrible death from kidney failure… so now it's completely

		different and you can do things. I still lead… well…well… you try and lead a normal-ish life Peter: Oh I'm just used to it know I just make it up, when I can be bothered to do it, when I can find one in Marks and Spencer's big enough I mean you get used… you get used to it so you start to make jokes about it.... because you hear the same question form all these people you just try and find ways of making light of the situation. Peter: I'm looking to the future, I'm retraining, I've gone back to college to retrain and hopefully that's the start of a new career…
Hidden Diagnosis	Public profile of ESRD	John: The whole kidney thing it's just so small no one knows anything about it. I think that's where it's wrong I think...it...needs to be brought out a little bit more...because as the... you folks say there's more and more people coming onto it but they've no idea John: I do think er…as I said earlier on I think the main problem is is that there's not anything out there.. you know...you hear about you know I mean obviously they're all horrible ..obviously you've got your cancers, strokes heart attacks, diabetes and things like that (sigh) and you just… you don't know anything there's nothing out there in the world that's telling you to get this checked like that advert for a stroke...the fast is it? Tom: People don't understand unless they got a problem like yours, nobody knows about it, nobody's heard of it. Sandeep: and if you tell someone, you know, I'm not allowed this food they don't understand, well Asian people don't understand any way, they totally don't understand. It's er…really frustrating... I get the feeling Asian people don't want to know if you're ill Mark: Er.. at the beginning like I said it was… very… very…hard for me to take in because it was all me I sort of hit the ground running…some people they knew what was going to happen…but with me… it happened that fast so I had a lot of information and that to take in… so it was very new to me everything… you don't know anything about it…then you have to. Naraj: People don't know about it, you have to explain everything. Niraj: …for the first 10 years on CAPD people probably couldn't tell the difference Peter: it's a terrible illness to have whatever age you are but society now seems to be focusing more on the older people and not on your working man I'm not being discriminating but that just how it seems to be, there seems to be more research on old people having the illness whereas they should be looking at people of my own age and helping people of my age a- getting back to work and with transplants and everything like that er… but nothing seems to be happening… Peter: So that's why I've gone back to college to retrain er… because I don't feel that I'm getting the support from the correct people that don't understand, that don't know where to put you within the benefit system… cos obviously some

		people are working, some are not, some are well, some are not so… so there's no… you're not… oh he's got kidney failure we'll give him these benefits, here what he'll have… it's oh how well are you? What can you do? What can't you do? Peter: it just seems to be… like if you went and spoke to Joe blogs off the street and said if I gave you renal failure what's the first 3 things that come into your head and a lot of them would probably say it was an old person illness a lot would say , when your transplant due (laughs) er… and then they'd probably know dialysis but they wouldn't know anything else. What impact it makes on your life…erm… I mean it's very, very hard when you've got a young daughter because they want... the want… but anybody that's got family in doing this it's very hard… so the level of understanding people have is non-existent, there isn't any Peter: because I think in the lime light there's not many people come forward that's had renal failure or going through it, it's not in the limelight… I think if you found out, if one of the a-list celebrities in this country and got it you'd find out a lot more information about it would become available to a lot of people it seems to be a taboo to a lot of people, I'm part of a little circle outside that circle knows nothing it's like the masons you know (laughs) a really tight knit group that how it seems to be, that if you were outside, there must be loads of people sat out there feeling not well and if there was loads of information out there perhaps that would have helped them before it's too late…
	Tangible illness	Sandeep: I don't really I don't really talk about my illness unless they've got a problem with, you know, their health and then, sometimes I'd say yeah I've got a problem I'm on dialysis at the hospital otherwise I don't really discuss it with Sandeep: I keep it hush, hush but your arms a mess and you can't... you can't…I never walk around with my sleeve up because...you know… because people ask and stuff so you sort of hide it really Tom: You can't show it to people, they know you're ill, but there's no you know…proof… John: I will argue tooth and nail with an illness cause I don't think I've got an illness I've got a condition, you know, my kidneys don't work and I'm not you know I don't feel ill I mean alright it knocks me wrong but (sigh) like you know when I come off the machine I'll go to bed er later on and er… but I don't see it as an illness I just see it as something that's just gone wrong in my body erm...and that's the way I see it I don't rate is as a illness you know there are illnesses you know John: I don't rate is as a illness you know there are illnesses you know out there but if you look out there (points toward unit) some of them look quite alright you wouldn't think there was anything wrong to look at them that there's anything wrong with us so you know if you look at cancer patients they...look like there ill whereas I don't think none of us do half the time depending on the day of course but I don't think it's an illness I just think we...it's a condition we have Mark: … … … I'd like to try and ignore it and say no I'm not ill but it's got a habit of kicking me in the teeth (Laughs) so yeah I would say I'm ill…even if it doesn't seem obvious.

		Mark: People don't realize, they don't see what you go through…what your wife goes through. Naraj: I see myself as having a condition… I'm ill when I'm not well… and right now I'm not ill I have a condition I'm ok um… so… for me the difference is basically this is something I have to deal with… when the symptoms of the condition get worse I become ill… then people recognise it as well Niraj: Someone who where they're have symptoms which actually hinder their normal day to day activities and… you know… day to day running basically if you had the flu you're ill.. if… if… you have… erm… if you had weaknesses and general lethargy and then you could be classed as being ill but right now I'm not ill I have a condition… I'm not as fit as I'd like to be able to be… I'm not I'm not able to do the things I could do before… Peter: Erm… unless someone asks I don't say cos… if you turn round to someone and say that you're ill they treat you different… Peter: Cos on the outside I don't look any different from a normal person it's not like I've got a limb missing or something, you take a leg of or an arm off or if I lost an eye… looking at me there's no difference, they only difference is my arm where the needles got in but if I've got me jacket on which I usually do erm… no one 'll know any difference about me.

So do you think having kidney disease and stating dialysis has made a difference to the way you see yourself?

maintaining the self

No...no, I still think I'm about the same I'm the same person

Ok

I wouldn't say theres any difference whatsoever in me

Mmm, ok, would have described your self differently in any way before all this?

Shock

Having a → narrative (whole section)

Time

~~For~~ Journey to diagnosis

Hope

Acceptance

No, it was really weird because when I came in again everything was just going so wrong (sigh) I had no idea I had renal failure whatsoever I came I with a er...a very low blood count and the Dr that seen me send me for a blood test on the Friday and er… that Friday night he rings me up and goes you've got to go to hospital so I come straight to hospital and I don't know anything about it whatsoever I just that I was unhealthy and they tested me and they said oh… we'll give you a bit of iron and then hopefully you know…you can go home the next day and I was went oh well that's fair enough…that's not too bad and then they came back later on and went your kidneys don't work and I said oh and they just the way I thought about it was just that's another thing wrong with me and er… that was the way a thought about it oh you know ok

Belief in being same person (maintain self) seems this is importance that although health is different self is stable.

Very short replies from a chatty man, more impact, more certainty or denial perhaps?

Sudden diagnosis - shock.

This passage is his story to diagnosis, feels practised, important to have a narrative as a renal patient or as a journey to diagnosis?

shows acceptance of what told at each stage, Lets it happen?

that's what's wrong with me…and so in a way it was probably a blessing that they knew…

Mm

….and er…so it was just one of those things where I just though oh well, there you go (laughs) as daft as it sounds I just turned around to my self and said at least you ain't got cancer …

Mm

So…but yes it was just knowing like when you read the booklets

Yes

Like all the signs were there ticked off but I didn't have a clue before hand and it been going on for ages as well...well for about half a year I'd say where it all deteriorated

Mm

And so you thing others see you differently since that's all happened and you've started dialysis?

I don't' think so... er... no... er…no cause well…my…family all…think I am what I am…er… er no I don't think so I think they still see the

Positives of diagnosis

Acceptance / Adjustment

Humor

It could be worse

Hindsight

Getting information

Hindsight

Journey to diagnosis

Threatened sense of self

maintaining sense of self

Journey long and difficult having the answer=the diagnosis felt like a 'blessing' Knowing is better.

Acceptance and adjustment here; also humor, not getting down or negative

Important it could be worse, that feels hopeful, actl perspective

Hind sight. seeing it coming retrospectively. Lack of knowledge and public profile

Sudden; shock

Lots of hesitation, perhaps his families view is different incongruent with his own. but keen to be same to maintain 'self' despite diagnosis

same person so I'd say yeah…er...they still see they same person, same me, I don't know if that's good idea or not but er… there's no change in me…

Ok…and what does the term illness mean to you and how would you define it?

I will argue tooth and nail with an illness cause I don't think I've got an illness I've got a condition, you know, my kidneys don't work and I'm not you know I don't feel ill I mean alright it knocks me wrong but (sigh) like you know when I come off the machine I'll got to bed er later on and er… but I don't see it as an illness I just see it as something that's just gone wrong in my body erm...and that's they way I see it I don't rate is as a illness you know there are illnesses you know out there but if you look out there (points toward unit) some of them look quite alright you wouldn't think there was anything wrong to look at them that there's anything wrong with us so you know if you look at cancer patients they...look like there ill whereas I don't think none of us do half the time depending on the day of course but I don't think it's an illness I just think we...it's a condition we have

So how would you define and illness?

(Sigh) Er… things when you can't get up in the morning you know, you try and lift your head up and you've just go nothing in you to do it whatsoever you can't do anything stay your in a wheel chair you know

Importance of being seen as same person.

Defiance in the face of diagnosis

Defining ESRF, condition VS. illness

Failure of the kidneys

Fatigue

Betrayed by the body

(Then) the renal community

Appearing well

Secret diagnosis

Could be worse

Tangible illness

Appearing well

Uncertainty

Condition vs illness

Rejecting the sick role

Could be worse

Feels almost desperate as speaks not to be seen as different.

Question from family perspective but self statement at end – almost defiant of disorder – almost like the diagnosis has nothing to do with him.

Almost externalising 'my kidneys' but a feeling of seperateness from the self

Almost fights against illness as a label. feels unhelpful to him.

'Then' but conveyed in a warm way, togetherness, like a community; appears well almost a secret diagnosis ups and downs acknowledge (depends on the day)

Again importance somebody is worse off as you still bey useful and active